

# House of Commons Northern Ireland Affairs Committee

# Health funding in Northern Ireland

# **First Report of Session 2019**

Report, together with formal minutes relating to the report

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#### **Northern Ireland Affairs Committee**

The Northern Ireland Affairs Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Northern Ireland Office (but excluding individual cases and advice given by the Crown Solicitor); and other matters within the responsibilities of the Secretary of State for Northern Ireland (but excluding the expenditure, administration and policy of the Office of the Director of Public Prosecutions, Northern Ireland and the drafting of legislation by the Office of the Legislative Counsel).

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# **Summary**

The most urgent issue currently facing health and social care in Northern Ireland is how to transform a healthcare system based on an acute, reactive model of care into a proactive system with the capacity to meet the needs of increasing numbers of older people with chronic, complex conditions. Support for transformation receives widespread, cross-party support on the understanding that, without change, the system will deteriorate until services collapse under pressure.

Transformation requires strategic, long-term investment and scrutiny of the difficult decisions that will have to be made. This has been impeded by the ongoing absence of the Northern Ireland Assembly and Executive, without which it has not been possible for policy priorities to be set and appropriately resourced. Ultimately, it will be up to Northern Ireland's elected representatives to bring about the change the system requires. However, in the meantime measures must be taken to prevent Northern Ireland's health system from falling behind the rest of the United Kingdom and the needs of service users. While the announcement by the Secretary of State in 2018 of funding ring-fenced for transformation was welcomed, the current model of non-recurrent funding over a two-year period is not suited to long-term planning. We recommend that a longer-term funding settlement is sought to sustain service transformation.

In addition to an inadequate funding model, we found that many areas of healthcare were operating within a policy vacuum. In the absence of comprehensive strategies in areas such as cancer, mental health and oral health, clear direction for investment has been lacking and funding has been funnelled into plugging holes in existing services rather than service transformation. We have recommended that preparatory work begin on developing strategies in these areas to enable more strategic investment in the future.

Social care is integrated with healthcare in Northern Ireland and can play a vital role in early intervention, preventing people from being admitted to hospital and subsequently facilitating their discharge. However, the current social care workforce is undervalued and in need of recognition. Most social care is delivered by the independent sector yet disparities in wages, terms and conditions and career development pathways between the statutory and independent sectors have led to high levels of churn for independent providers. Steps need to be taken to consolidate the social care workforce and raise the value of social care across the board.

A number of critical areas of healthcare have been subject to prolonged underinvestment. These include mental health, particularly Child and Adolescent Mental Health Services (CAHMS) and the community pharmacy network, much of which is finding it increasingly difficult to remain open. These are areas which have a critical role in reducing demand on acute services and delivering long-term savings for the Department. Funding gaps are acknowledged by the Health and Social Care Board and other bodies and these gaps must be closed if the full potential of these services is to be utilised.

While the impasse at Stormont remains the significant impediment to addressing the challenges currently facing Northern Ireland's health service measures must be taken in the interim to prevent the service from deteriorating further. We believe that the recommendations in this report will go some way towards meeting those challenges and prevent the service from falling further behind.

# Introduction

#### Health and Social Care in Northern Ireland

Health and Social Care (HSC) is the publicly funded health service of Northern Ireland. The HSC grew out of the Health Services Act (Northern Ireland) 1948 which made provision for a comprehensive health service in line with that introduced in England, Scotland and Wales the same year. Northern Ireland's health service came to be modelled differently to that implemented in other parts of the United Kingdom. Responsibility for service procurement fell to a number of statutory bodies while the authority of the Ministry of Health and Local Government (later to become the Department of Health and Social Services under direct rule; the Department of Health, Social Services and Public Safety in 1999 following the return of devolution; and finally the Department of Health from 2016 onwards) was restricted to the coordination of services. In December 1969, against a backdrop of increasing unease with the structures of local government, a review body was appointed to examine proposals for reshaping these structures. This culminated in the Macrory report of 1970 which advocated "a great reduction in the number of decision-making bodies and of the levels of executive power." Its recommendations laid the groundwork for reforms implemented in 1973 shortly after the introduction of direct rule whereby the existing health authorities and committees were abolished and replaced with four new health and social services boards. The reforms incorporated the integration of health and social care, a model justified by then Minister of State Lord Windlesham at the newly created Northern Ireland Office on the basis that:<sup>2</sup>

In many fields the health of a community and its social needs are interrelated. The elderly, the handicapped and the mentally ill, for example, are particularly vulnerable groups in need of both medical and social care. The combined administrative structure will enable the health and social services for these groups to be fully co-ordinated.

The integration of health and social care is now widely advocated as a desirable model and remains a long-term ambition of the National Health Service.

2. Following the signing of the Belfast/Good Friday Agreement in 1998, the newly constituted Executive's Programme for Government called for the development of "a cross-cutting public health strategy which maximises, across all sectors, our efforts to improve health and well being and reduce health inequalities." The resulting strategy *Investing for Health* was launched in 2002 and advocated a cross-disciplinary and multisectoral approach aimed at addressing the wider social determinants of health. In 2003, the Review of Public Administration concluded that the four health and social services boards would be dissolved and their functions assumed by regional organisations that would better facilitate the aims of *Investing for Health*. These were brought forward by the Health and Social Care (Reform) Act 2009 which established the Health and Social Care Board, Public Health Agency, Regional Business Services Organisation and the Patient and Client Council. The restructuring aimed at a more streamlined and accountable

<sup>1</sup> Patrick A. Macrory, Review Body on Local Government in Northern Ireland, June 1970, paragraph 12

<sup>2</sup> House of Lords Hansard, 27 July 1972, Volume 333, Column 1543

<sup>3</sup> Northern Ireland Executive, Draft Programme for Government (2000), page 30

model that would maximise resources for front-line services, place greater emphasis on prevention and provide support for vulnerable people to live independently in the community for as long as possible.<sup>4</sup>

- 3. Northern Ireland's public health system under the direction of the Department of Health is currently structured around:
  - Five regional Health and Social Care Trusts with responsibility for the management and administration of regional health and social care facilities and services (the Belfast, Northern, Southern, South Eastern and Western HSC Trusts) together with the Northern Ireland Ambulance Trust;
  - the Health and Social Care Board, which commissions services, performance manages the HSC Trusts and deploys funding from the Northern Ireland Executive;
  - the Public Health agency, a multi-professional body which aims at improving and protecting public health and social well-being, reducing health inequalities and professionally assists in the commissioning process;
  - and a number of other bodies including the Patient and Client Council, the Business Services Organisation, Regulation and Quality Improvement Authority, Northern Ireland Ad Litem Agency and the Northern Ireland Social Care Council.
- 4. In March 2016, the Health Minister announced that the Health and Social Care Board would be abolished with all commissioning powers transferred to the Department of Health and a new group established to hold the five Trusts to account.<sup>5</sup> However, since the collapse of the Executive this has not happened.
- 5. The HSC serves a population of over 1.8 million people of which 308,200 people (16.4 per cent) are aged 65 or over.<sup>6</sup> Rising demand from increasing numbers of older service users with complex needs is projected to place unsustainable pressure on the health service as it is modelled currently. Health policy, in response, has aimed at diverting care away from hospitals and towards community-based services. The 'transformation agenda' has received cross-party support on the basis of "an unassailable case for change" but while some progress has been made towards a realignment of services the agenda continues to be hampered by the collapse of the Northern Ireland Executive.

#### Funding following the collapse of the Northern Ireland Executive

6. In January 2017, following the resignation of the Deputy First Minister, the Northern Ireland Executive collapsed. There has been no devolved government in Northern Ireland since this date and consequently no Minister of Health. Departments are unable to lawfully deploy funds until funding has been appropriated to them and an Appropriation Act can not be passed until a Budget has been set. In usual circumstances the Minister of

<sup>4</sup> Department of Health, Social Services and Public Safety, Framework Document, 30 September 2011, page 3

<sup>5</sup> BBC News, Health and Social Care Board to be abolished by NI minister, 24 March 2016

<sup>6</sup> Northern Ireland Statistics and Research Agency, 2018 Mid-year Population Estimates for Northern Ireland, 26 June 2019, page 9

<sup>7</sup> Systems, Not Structures: Changing health and social care, page 9

Finance would present a Draft Budget to the Northern Ireland Assembly for debate and approval. However, this is not possible in the absence of a functioning Executive and by the time the Executive collapsed a Budget for 2017–18 had not been set.

- 7. Section 59 of the Northern Ireland Act 1998 authorises the Northern Ireland Civil Service to issue 75 per cent of the previous year's Budget out of the Consolidated Fund of Northern Ireland if an Appropriation Act has not been passed three working days before the end of the financial year, rising to 95 per cent if an Appropriation Act is not in place by the end of July. In March 2017 the Permanent Secretary at the Department of Finance exercised these powers, stating this would "enable cash to continue to flow to maintain the provision of public services" but that they were "not a substitute for a Budget agreed by an Executive" and that "the prioritisation and allocation of financial resources is a matter for Ministers."
- 8. The Civil Service advised the Secretary of State for Northern Ireland that November was the latest point at which a Budget could be set before funds would begin to run out. To avoid this, on 16 November 2017 the Government passed the Northern Ireland Budget Act 2017 which authorised Northern Ireland Departments and other bodies to incur expenditure and use resources as if it were a Budget passed by the Northern Ireland Assembly. The Secretary of State remarked that the Departmental allocations set out in the Bill were those "recommended by the Northern Ireland Civil Service" which "sought as far as is possible to reflect the priorities of the previous Executive." 10
- 9. In anticipation of the need for a 2018–19 Budget, the Department of Finance published a briefing paper in December 2017 setting out broad strategic issues that would inform an incoming Executive's decisions on setting a Budget for 2018–19 and 2019–20. Its assessment was that for an effective Budget to be delivered it should be agreed no later than early February 2018 and that, were Departments to continue spending on current profiles, particularly in health and education, "the available Budget for 2018–19 would be significantly exceeded." The briefing paper highlighted the rising cost of existing models of health service provision and the need for transformational change.
- 10. In March 2018 the Secretary of State set out Budget allocations for 2018–19. In addition to capital and resource allocations the Secretary of State set out the allocation of funds drawn from the financial annex to the Confidence and Supply Agreement between the Government and Democratic Unionist Party. This included £80 million to support immediate health and education pressures; £10 million for mental health; and £100 million to support transformation of the health service along with £4 million to "prepare the ground" for transformation. The Government subsequently passed the Northern Ireland Budget Act 2018 which authorised, with some adjustments, those appropriations set out in the March statement. The Explanatory Notes to the Bill stated: 14

This Act is a minimal step to ensure that public services can continue to be provided in Northern Ireland for the full financial year. It leaves in place the

- 8 Department of Finance, Department provides Budget clarification, 28 March 2017
- 9 House of Commons Library, Northern Ireland Budget Bill 2017–19 [Bill 123], Briefing Paper No. CBP 8122, 9 November 2017, page 3
- 10 UK Government, Secretary of State's Oral Statement on the NI Budget Bill, 13 November 2017
- 11 Department of Finance, Briefing on Northern Ireland Budgetary Outlook 2018–20, 18 December 2017, page 7
- 12 Ibid., pp. 71-71
- 13 UK Parliament, Northern Ireland Finances: Written statement—HCWS527, 8 March 2018
- 14 Northern Ireland Budget Act 2018, Explanatory Notes, paragraph 9

requirement for devolved spending decisions to be made by the Northern Ireland Executive or, in the ongoing absence of Ministers, the Northern Ireland Civil Service.

11. On 28 February 2019 the Secretary of State announced Budget allocations for 2019–20. These allocations included: a real-terms increase in resource funding for the Department of Health along with a further £100 million for health service transformation; £4 million to "prepare the ground" for transformation; and £10 million for mental health drawn from the financial annex to the Confidence and Supply Agreement. These allocations also allowed for £130 million of existing 2019–20 capital funding to be used to address public service resource pressures and up to £85 million of resource and £8 million of capital funding to be carried forward from 2018–19 into 2019–20. In her statement to the House the Secretary of State remarked:<sup>15</sup>

In the absence of local Ministers, and given the proximity of the next financial year, it would not be appropriate for the UK Government to seek to take fundamental decisions about service delivery and transformation. Those are strategic decisions that should be taken by locally elected and accountable Ministers in a new devolved government. Yet we must act to secure public services and enable Northern Ireland departments to meet urgent pressures in health and education and protect spending to other departments with core front line public services. That is what this budget settlement will do, by protecting and preserving public services within challenging fiscal constraints.

#### **Decision-making in the absence of Ministers**

- 12. Article 4 of The Departments (Northern Ireland) Order 1999 requires that "the functions of a department shall at all times be exercised subject to the direction and control of the Minister." Northern Ireland Departments had interpreted this as only applying while Ministers were in post and continued to take decisions "reluctantly and only after taking legal advice" following the collapse of the Executive.
- 13. In September 2017 the Department for Infrastructure granted planning permission for a residual waste treatment facility at Hightown Quarry in County Antrim. A judicial review was subsequently instigated by a local resident and on 14 May 2018 Mrs Justice Keegan ruled that the Department had acted unlawfully, stating that "the provisions of the 1999 Order are clear. The language is expressed in mandatory terms by inclusion of the word *shall*" and "I do not consider that Parliament can have intended that such decision making would continue in Northern Ireland in the absence of Ministers without the protection of democratic accountability." An appeal against the decision was dismissed by the Court of Appeal on 6 July 2018.<sup>20</sup>

<sup>15</sup> UK Parliament, Northern Ireland Finances: Written statement—HCWS1370, 28 February 2019

<sup>16</sup> The Departments (Northern Ireland) Order 1999, Article 4(1)

<sup>17</sup> The Executive Office, Head of Civil Service comments on Dfl's intention to appeal judgment, 16 May 2018

<sup>18</sup> Department for Infrastructure, <u>Planning permission granted for arc21 Residual Waste Treatment Facility</u>, 13 September 2017

<sup>19</sup> High Court of Justice, Buick's (Colin) Application (ARC21), [2018] NIQB 43

<sup>20</sup> Court of Appeal, Buick's (Colin) Application as Chair Person of NOARC 21, [2018] NICA 26

14. In September 2018 the Secretary of State remarked on a number of examples where a lack of Ministerial decision making was holding Northern Ireland back, announcing her intention to bring forward legislation that would "include provisions to give greater clarity and certainty to enable Northern Ireland Departments to continue to take decisions in Northern Ireland in the public interest and to ensure the continued delivery of public services." In November 2018 the Government passed the Northern Ireland (Executive Formation and Exercise of Functions) Act 2018, of which Section 3(1) states:<sup>22</sup>

The absence of Northern Ireland Ministers does not prevent a senior officer of a Northern Ireland department from exercising a function of the department during the period for forming an Executive if the officer is satisfied that it is in the public interest to exercise the function during that period.

The associated guidance on decision-making issued by the Secretary of State clarified that:<sup>23</sup>

Any major policy decisions, such as the initiation of a new policy, programme or scheme, including new major public expenditure commitments, or a major change of an existing policy, programme or scheme, should normally be left for Ministers to decide or agree. [ ... ] NI departments should then consider whether there is a public interest in taking a decision rather than deferring a decision during the period for Executive formation.

The guidance goes on to list a set of principles that senior officers should take into account when considering whether a decision can be taken in the public interest. These include:<sup>24</sup>

- The principle that it is a priority to maintain the delivery of public services as sustainably and efficiently as possible, working towards the previous Executive's stated objective of improving wellbeing for all—by tackling disadvantage and driving economic growth.
- The principle that the priorities and commitments of the former Executive and Minister(s) should be followed unless there is an exceptional circumstance such as a significant emerging challenge, new strong objective evidence, or significant changing circumstances which lead senior officials to conclude that it is no longer in the public interest to do so.
- The principle that opportunities should be taken to work towards the 12 outcomes published in the 2018–19 Outcomes Delivery Plan, which is based on the draft Programme for Government developed in conjunction with the political parties of the previous Executive.
- The principle that the consequences of deferring decisions, particularly in terms of the financial, economic, environmental, legal or social impact should be considered and significant detriment avoided.

<sup>21</sup> House of Commons Hansard, 6 September 2018, Volume 646, Column 347

<sup>22</sup> Northern Ireland (Executive Formation and Exercise of Functions) Act 2018, Section 3(1)

Guidance on decision-making for Northern Ireland Departments during the period for Northern Ireland Executive formation, November 2018, para. 9–10

Guidance on decision-making for Northern Ireland Departments during the period for Northern Ireland Executive formation, November 2018, paragraph 11

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#### **Our inquiry**

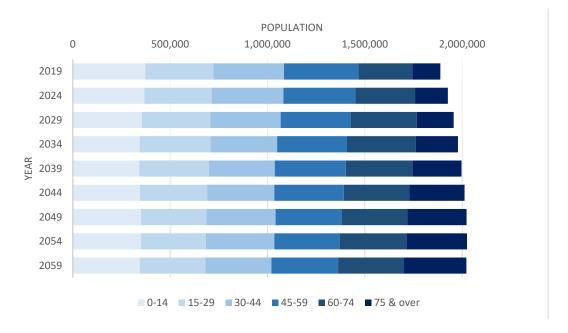
- 15. The absence of MLAs at Stormont has meant that representatives in Northern Ireland have not been able to scrutinise budgets set by Westminster or decisions made by civil servants at the Department of Health. We agreed that there was a pressing need for scrutiny of these decisions and in July we launched our inquiry into health funding in Northern Ireland. The inquiry aimed to examine whether funding was sufficient to sustain and improve services; how Confidence and Supply funding earmarked for health was being spent; and how funding could be best deployed to ensure value for money.
- 16. We began our inquiry with a call for written evidence and received a large number of submissions from a range of statutory, community and voluntary healthcare providers, professional associations, pharmaceutical companies and healthcare charities. Starting in September we held oral evidence sessions with the Health and Social Care Board and Public Health Agency; cancer charities; social care providers and associations; mental health charities and professionals; service users; the Chief Medical Officer; and the Department of Health. Healthcare is a broad subject and, due to limits on time and the evidence made available to us there were some areas that our inquiry was unable to cover. However, the conclusions of this report are based on the evidence we received and we would like to thank everyone who engaged with the inquiry, particularly Melanie Kennedy, Catherine O'Reilly and Rev. Dr. Scott Peddie for sharing their experiences as service users with the Committee.
- 17. In the absence of elected politicians the Department of Health has continued to take decisions on healthcare. We recognise that many of these decisions have been difficult in the context of mounting pressures on services, limited resources and the pressing need to bring about transformational change across the system. Our inquiry consequently deals with many matters that are ordinarily devolved. However, many stakeholders welcomed the Committee's engagement with these matters and, though the preferred solution remains a restored Assembly and Executive, there was a clear desire from the people we spoke to for effective decision-making and the urgency of many of the decisions that need to be taken. Where we have made specific recommendations to the Department the Committee has been mindful of the Secretary of State's guidance on when decisions should be taken in the public interest, in particular that priority should be given to maintaining the delivery of public services as sustainably and efficiently as possible; working towards the previous Executive's stated objective of improving wellbeing for all; following the priorities and commitments of the former Executive and Health Minister; and the principle that the consequences of deferring decisions should be considered and significant detriment avoided.

# **1** Transformation

#### An ageing population

18. According to most recent estimates Northern Ireland has a population of 1.88 million.<sup>25</sup> The population in mid-2018 grew by 10,800 people (0.6 per cent) from mid-2017, mainly due to natural growth (births minus deaths) with some net inward migration.<sup>26</sup> Alongside moderate population growth and in common with global trends, the proportion of adults in Northern Ireland aged 65 or older is rapidly increasing. In mid-2018, 308,200 people (16.4 per cent) were aged 65 or older of which 37,700 (2 per cent) were 85 or older.<sup>27</sup> This represents an increase of 1.7 per cent and 1.5 per cent respectively from mid-2017.<sup>28</sup> By contrast, the number of children aged 0–15 years increased by just 0.7 per cent.<sup>29</sup> In the last decade the median age (the age at which half the population is older and half is younger) has risen from 30.4 years to 38.7 years<sup>30</sup> and on current trends it is forecast that the number of people aged 65 or older will exceed the number of children aged 0–15 years by mid-2028.<sup>31</sup>

Figure 2: Projected population of Northern Ireland by age band, 2019–2059



Source: Northern Ireland Statistics and Research Agency, Principal projection—projection summary (2016–2066), 26 October 2017

19. These demographics necessitate a transformation in how health services are structured and delivered. As the population ages the patterns of demand it places on the health service change—incidences of chronic health conditions including cardiovascular disease, hypertension, osteoarthritis and diabetes increase with age as do rates of disability and

<sup>25</sup> Northern Ireland Statistics and Research Agency, 2018 Mid-year Population Estimates for Northern Ireland, 26 June 2019, page 1

<sup>26</sup> Ibid., pp. 2–3

<sup>27</sup> Ibid., page 9

<sup>28</sup> Ibid., page 1

<sup>29</sup> Ibid., page 7

<sup>30</sup> Ibid., page 5

<sup>31</sup> Ibid., page 5

cognitive conditions including dementia.<sup>32</sup> The health needs of a population also become more complex as people age, with older people more likely to be living with multiple chronic conditions at the same time.<sup>33</sup>

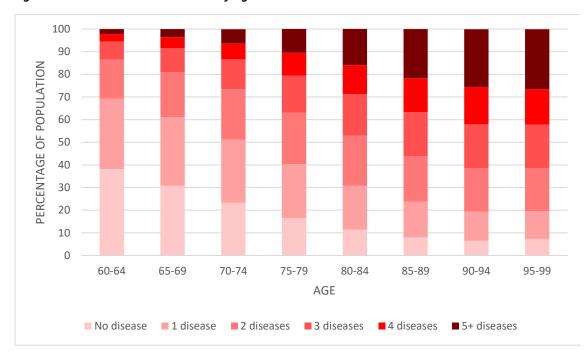


Figure 3: Number of co-morbidities by age band

Source: Age UK, The Age UK almanac of disease profiles in later life, 26 October 2017, page 40

As the number of patients with complex, long-term health needs increases pressure mounts on hospitals, leading to decreased capacity in the acute sector and sub-optimal management of conditions that could be better managed elsewhere.

#### The transformation agenda

- 20. In response to these changes, along with rising patient expectations and the opportunities opened up by technological advances, a broad consensus has developed around the need to move away from the acute care model centred on hospitals and towards a more community-based, integrated model of patient-centred care. A number of strategic frameworks have laid the groundwork for this approach, including *Caring for People Beyond Tomorrow* (2005) which sets out a 20-year framework for the transformation of primary care; *Transforming Your Care* (2011) which made a number of recommendations on the future shape and direction for health and social care services; and *The Right Time, The Right Place* (2014) which examined the application of health and social care governance arrangements.
- 21. The current direction for health and social care reform in Northern Ireland was set out by the clinically-led, expert panel chaired by Professor Rafael Bengoa in 2016 and appointed with the remit of delivering "the configuration of health and social care

<sup>32</sup> Efraim Jaul and Jeremy Barron, Age-Related Diseases and Clinical and Public Health Implications for the 85 Years
Old and Over Population, 11 December 2017

Age UK, The Age UK almanac of disease profiles in later life, 26 October 2017, page 40

services commensurate with ensuring world-class standards of care"<sup>34</sup> as recommended by Sir Liam Donaldson in *The Right Time, The Right Place* (2014). Its report, *Systems, Not Structures* (usually referred to as the Bengoa report) found an "unassailable case for change"<sup>35</sup> with the existing system struggling to sustain services in the face of changing circumstances. Along with pressures on the HSC from rising patient demand the report also identified severe difficulties in recruiting and retaining staff;<sup>36</sup> insufficient capacity in the social care sector impacting on acute care capacity;<sup>37</sup> and financial unsustainability—estimating that as currently configured the HSC would require at least a 6 per cent budget increase year on year merely to maintain current levels of performance.<sup>38</sup> The review concluded that:<sup>39</sup>

Without systematic and planned change, already stretched services will undoubtedly be forced into unplanned change through fire-fighting and crisis. The stark options facing the HSC system are either to resist change and see services deteriorate to the point of collapse over time, or to embrace transformation and work to create a modern, sustainable service that is properly equipped to help people stay as healthy as possible and to provide them with the right type of care when they need it.

- 22. The report contained a number of recommendations for the direction and delivery of service transformation. It highlighted the fragmented and reactive nature of the current model and advocated a move towards 'accountable care systems' whereby the provider sector—encompassing primary care, the HSC Trusts and the independent and voluntary sectors—adopt collective responsibility for the health and social care needs of defined populations under joint budgets. This would enable better continuity of care for patients; better integration across services and professions; a structure in which patients could participate actively in their own care; a shift in accountability to the provider level; and ultimately better outcomes. It highlighted Integrated Care Partnerships and GP Federations as model examples of existing networks to be built on.<sup>40</sup> The report also recommended investing in eHealth and empowering non-medical staff, such as nurses and pharmacists, to make the best use of their skills. 41 While advocating transformation as the only long-term solution, the panel also acknowledged that excessive waiting times for elective care had damaged public trust in the HSC and that efforts should be made to stabilise the system in the short-term. 42 To enable service transformation the panel recommended establishing a dedicated, ring-fenced transformation fund. 43
- 23. *Bengoa* was followed up the same year by *Delivering Together* (2016)—a 10-year road-map for transforming health and social care based on *Bengoa's* recommendations. The strategy reiterates the challenges identified in *Bengoa*, namely the negative impact of current delivery models on the quality and experience of care for service users;<sup>44</sup> the

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34
      The Right Time, The Right Place, December 2014, page 44
35
      Systems, Not Structures: Changing Health and Social Care, 25 October 2016, page 9
36
      Ibid., page 22
37
      Ibid., page 21
38
      Ibid., page 33
39
      Ibid., page 11
      Ibid., pp. 42-44
41
      Ibid., page 51
42
      Ibid., page 64
43
      Health and Wellbeing 2026: Delivering Together, October 2016, page 6
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thin spread of HSC resources across an excessive number of sites;<sup>45</sup> difficulties in filling vacant posts and an over-reliance on locums;<sup>46</sup> rising demand and pressures from an aging population;<sup>47</sup> and the need to tackle health inequalities.<sup>48</sup> The strategy aimed at an holistic, person-centred approach to health and social care with a focus on "prevention, early intervention, supporting independence and wellbeing"<sup>49</sup> with care to be designed in collaboration with service users and communities through close partnerships across organisational boundaries and delivered as close to home as possible.<sup>50</sup> It advocated: coproduction and co-design of services under a model of partnership working;<sup>51</sup> integrating quality improvement systems into HSC organisations and establishing an Improvement Institute to support developments in patient safety, regulation, evidence gathering, data analytics and user experience;<sup>52</sup> investment in the HSC workforce and the development of a workforce strategy to cover recruitment and retention, new job roles and reskilling and upskilling initiatives;<sup>53</sup> a flattening of unnecessary hierarchies to facilitate professional engagement in the management and leadership of services;<sup>54</sup> and better use of technology and data to improve outcomes for patients and free up time for front line staff.<sup>55</sup>

- 24. As part of the Confidence and Supply Agreement, £200 million of funding was made available over a two-year period beginning in 2018–19 to resource these aims. In 2018–19, £100 million was allocated to the following areas: $^{56}$ 
  - £30 million to help tackle elective care waiting lists;
  - £15 million to support services in primary care, including £5 million for the rollout of multidisciplinary teams;
  - £15 million to support development of the workforce;
  - £30 million to help reform hospital and community services, including investment in plans for Elective Care Centres and implementing new strategies for cancer services, stroke services, paediatric services, medicines optimisation, and diabetes care and prevention;
  - £5 million to help build capacity in communities and prevention, including significant investment in children's social services;
  - £5 million to enable the transformation process, including a range of targeted actions aimed at strengthening the voice of those who use and deliver HSC services, building capacity for quality improvement across the system, and investment in technology/supporting innovation.

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45 Ibid., page 6
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<sup>46</sup> Ibid., page 7

<sup>47</sup> Ibid., pp. 7–8

<sup>48</sup> Ibid., pp. 8–9 49 Ibid., page 11

<sup>49</sup> Ibid., page 11 50 Ibid., page 11

<sup>50</sup> Ibid., page 1151 Ibid., pp. 20–21

<sup>52</sup> Ibid., page 21

<sup>53</sup> Ibid., page 22

<sup>54</sup> Ibid., pp. 22-23

<sup>55</sup> Ibid., page 23

<sup>56</sup> Department of Health, Health and social care transformation funding announced, 9 May 2018

A further £100 million, together with £16 million re-profiled from the previous year, has funded a number of transformation projects into 2019–20. These include:<sup>57</sup>

- £52 million to reform community and hospital services, including day case surgery hubs, social services training, reviews of existing services such as pathology, imaging, bariatric and oncology, and investment in mental health services;
- £19 million to support the provision of practice-based physiotherapists, mental health specialists and social workers working alongside GPs in local practices;
- £14 million funding for the most clinically urgent cases on hospital waiting lists;
- £13 million to support the workforce in areas such as medical speciality training, physiotherapy training, GP development, leadership and training for ambulance staff, including training new paramedics and stabilising NI ambulance staffing numbers;
- £13 million to build capacity in communities; supporting more acute care to be accessed at home, and to support prevention, through new photo triage technology, and new cardiovascular prevention programmes;
- £5 million to enable meaningful co-production with those who use and deliver services, continued quality improvement and investments in modernising outdated IT systems.

#### **Delivering transformation**

25. The Committee heard unanimous support for the transformation agenda as set out in *Bengoa* and *Delivering Together*. However, significant concerns were raised over the non-recurrent, year-on-year funding model for delivering transformation. The Chartered Society of Physiotherapy told us that *Delivering Together* "requires a longer-term budget commitment to deliver it, rather than current care and maintenance approach where emergency budgets are allocated one year at a time." The Northern Ireland Commissioner for Children and Young People told us that "long-term transformational change requires long-term strategic planning that is matched with the required public funding to deliver it." She added that:

Across the health and social system, multi-year funding is essential to develop longer term plans, that are needed to address pressures across the system, rather than relying on short term initiatives and funding top ups.

26. This was a view shared by Action for Children, who told us that "transformative investments need to take a longer-term approach and not just cover a one to two-year Budget period." The Royal College of Surgeons of Edinburgh expressed "major concerns" that "the £100m [transformation fund] is a 'sticking plaster' without a long-term strategy and the foresight to ensure that the funds are used as effectively as possible."

<sup>57</sup> Department of Health, Transformation fund continues to support much-needed change, 4 July 2019

<sup>58</sup> Chartered Society of Physiotherapy (HTH0040)

<sup>59</sup> Northern Ireland Commissioner for Children and Young People (HTH0049)

<sup>60</sup> Action for Children (HTH0020)

The Royal College of Surgeons of Edinburgh (HTH0046)

27. The Committee heard how the deployment of transformation funds in the absence of long-term financial planning had led to sub-optimal results and in some cases created additional problems. The Royal College of Occupational Therapists raised the issue of posts being recruited on a temporary basis within the context of protracted financial uncertainty.<sup>62</sup> Ulster University told us that transformation funds received by the University to support workforce development could not be used to plan effectively in the absence of recurrent funding:<sup>63</sup>

As a result of confidence and supply funding, Ulster University has received an increase in the number of student places commissioned by the Department of Health for students beginning their studies in 2018. Whilst these increases are very welcome, the additional places will only be granted for this year, meaning we must plan to revert to the 2017 figures for each of these courses next year. The lack of long-term funding makes it difficult, not only for the University but for the whole sector to plan effectively, including the Department of Health itself.

The Royal College of Nursing placed the inadequacy of the current funding model within the broader context of a political situation that can not deliver on the sustained and meaningful change needed, noting that:<sup>64</sup>

Transformation of the health and social care system in Northern Ireland is a long-term process that is dependent upon an elected Assembly and Executive in addition to a number of factors, particularly workforce planning and development, and capital investment in the HSC estate, that are in themselves long-term. We do not believe that transformation in any meaningful sense will ever happen within the constraints of annual budgets, extraneous and non-recurrent sources of funding, or whilst there exists a simultaneous requirement to "balance the budget." [ ... ] Transformation requires committed and secure investment over a three–five year (at least) timeframe. It will not be delivered, or even meaningfully "pump-primed" in our judgement, through "funding in the short-term."

28. The Health and Social Care Board confirmed that there had been difficulties in deploying non-recurrent funding, telling the Committee that "to go from a standing start to £100 million of spend for just two years is [ ... ] extremely challenging." When asked whether this approach could be wasteful, the Director of Finance told us: 66

I think the projects that we are spending the funds on are the types of things that, if we had more funding in our core services, we would want to be doing anyway, but because our core budget [ ... ] is so constrained, we have very little development funding. I do not believe that any of the money from transformation will be wasted—far from it. I think that it allows us to pilot things in certain areas to ensure that they work before they are then bid for full recurrent funding to roll out to the whole of Northern Ireland.

<sup>62</sup> Royal College of Occupational Therapists (HTH0008)

<sup>63</sup> Ulster University (HTH0036)

<sup>64</sup> Royal College of Nursing (HTH0037)

<sup>65</sup> Q5

<sup>66 &</sup>lt;del>Q8</del>

The view that non-recurrent funding had been limited to preparatory work rather than on making truly transformative, long-term changes was also voiced by the Chief Medical Officer, Dr Michael McBride, who told us that transformation funding had allowed the Department to "do much preparatory work [ ... ] to put in place the foundations for a transformed health and social care system" but that "making permanent changes to the service model, making fundamental commitments to change in policy or strategy, or committing resources in the long term, will require the machinery of government and Ministers to be in place to make those decisions." In correspondence with the Committee, the Department of Health noted that "delivering the transformation agenda will require additional investment over a sustained period over and above what is required to run existing services, until the impact of transformation has been realised." 68

29. Transformation of Northern Ireland's health and social care services in line with the aims and recommendations of Bengoa and Delivering Together is needed urgently if services are to keep pace with the increasingly complex and evolving needs of an aging population. The Committee welcome funding ring-fenced for this purpose. However, the current model of non-recurrent funding over a two-year period is not suited to delivering the truly transformative and sustained change required. We recommend that, if an Executive is not in place by the end of this year, the UK Government work with the Department of Health and the Department of Finance to secure a multi-year funding settlement ring-fenced for transformation.

#### **Annual budgets**

30. The commissioning and budgetary cycle is currently set on an annual basis. We have heard how this is impeding long-term planning and service transformation. Dr Michael McBride told the Committee that annual budgets were not suited to delivering transformational change:<sup>69</sup>

Unfortunately and regrettably over the last number of years, we have been largely dependent on in-year monetary rounds and non-recurrent funding. It is very difficult and challenging to bring about change in the health service in a financial year. It is very difficult to bring about transformation when you have money that is non-recurrent. You need to recruit staff. You need to put new services in place. Longer-term budgetary cycles, more certainty, examination of what our baseline budgetary position is, and a continuation of moneys to allow us to transform the health service and that being ring-fenced, would be very advantageous.

31. The Northern Ireland Council for Voluntary Action drew attention to the impact successive annual budgets were having on the community and voluntary sectors:<sup>70</sup>

One-year budgets fuels stagnation and destroys proper planning. This is true for Northern Ireland as a whole, and particularly for voluntary and community sector organisations that have a financial arrangement with

<sup>67</sup> Q180

<sup>68</sup> Department of Health (NI) (HTH0050)

<sup>69</sup> Q194

<sup>70</sup> Northern Ireland Council for Voluntary Action (HTH0038)

government, for whom year-on-year uncertainty around continued funding and successive annual reductions in funding undermine organisations' ability to retain staff and sustain services.

- 32. Staffing difficulties under single-year budgets were also raised by Ulster University, which drew attention to the high vacancy rate for nurses in Northern Ireland, noting that due to the investment and planning required in the recruitment and training of nurses "a sustainable model of funding and commissioning is crucial to the future development of the nursing workforce." The University went on to "strongly recommend moving towards a three-year commissioning plan for pre-registration and post-registration nursing commissioning, and ensuring that appropriate levels of resource are allocated." Moves towards a minimum three-year budgetary cycle were also advocated by the British Red Cross. They told us that this would "provide a greater level of stability and enable implementing the vision of Delivering Together" and that "such a plan should be developed in partnership with patients, professionals and the wider sector, including the community and voluntary sector, and apply for all providers within the system."
- 33. Inspire, a charity and social enterprise delivering mental health-related services on the island of Ireland, was critical of the reluctance of the Government to revisit this funding model in the absence of a functioning Northern Ireland Executive:<sup>73</sup>

Continuing a failing funding formula cannot be said to be a sufficient legislative or political approach by Westminster. Any political response from a Westminster perspective that, if Northern Ireland wishes to manage its public services itself it should encourage its representatives to reach an agreement to reactivate the Stormont institutions, is counter-productive [ ... ] because overseeing the continued decline in health and social care provision will make restarting institutions and more pertinently, remedying the health service crisis more difficult.

- 34. A 2016 report by the Northern Ireland Assembly Public Accounts Committee supported calls for multi-year budgetary cycles. It noted the dependency of HSC Trusts on substantial financial support through in-year monitoring rounds that had the potential to mask underlying financial management difficulties and advocated a move towards three-year budgets to avoid annual constraints and place the Trusts on a sustainable footing.<sup>74</sup> In December 2018, the Northern Ireland Audit Office also advocated longer term financial planning and commissioning to "help move Trusts away from 'firefighting' short term pressures, and assist them in developing longer-term and better value for money solutions."<sup>75</sup>
- 35. The Department of Health told us that successive annual budgets combined with the need to reduce costs was impeding long-term change as the investment needed is unable to deliver savings in a single financial year:<sup>76</sup>

<sup>71</sup> Ulster University (HTH0036)

<sup>72</sup> British Red Cross (HTH0032)

<sup>73</sup> Inspire (HTH0045)

<sup>74</sup> Northern Ireland Assembly Public Accounts Committee, Report on General Report on the Health and Social Care Sector 2012–13 and 2013–14, 20 January 2016, pp. 11–12

<sup>75</sup> Northern Ireland Audit Office, General Report on the Health and Social Care Sector, 18 December 2018, page 3

<sup>76</sup> Department of Health (NI) (HTH0050)

We have been faced with consecutive single year budgets and the need to identify significant reductions in costs on an annual basis. The resultant impact is a focus on measures which can be taken to reduce costs, rather than measures which should be taken, as such measures will only have an impact in the longer term, and cannot deliver savings in a single financial year. Consequently, a short term focus means that cost reduction proposals may be counter strategic in nature and could result in increased cost pressures in future years. The challenging financial circumstances mean that hard choices are unavoidable and that there will be very limited scope for in-year additional initiatives to counter rising hospital waiting times and growing pressures elsewhere in the system. Without adequate funding being secured in future years, service reductions will be necessary across health and social care.

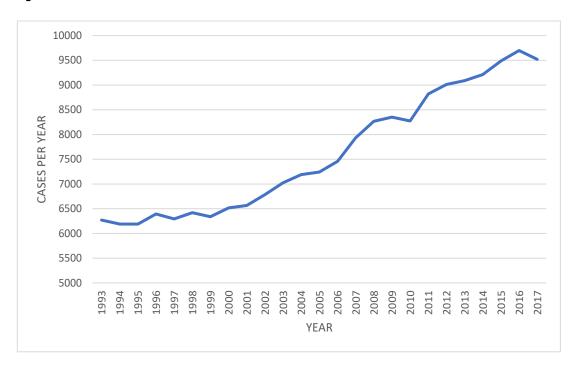
- 36. When asked by the Committee whether it would be helpful for the Secretary of State to legislate beyond the current financial year, the Permanent Secretary at the Department of Health told us: "I would not only welcome a budget for 2019–20; I would love a budget for the next two or three years to undertake that long-term planning. I think I could make bigger, more significant change in that context."
- 37. Successive one-year budgets are impeding planning and investment in Northern Ireland's health and social care services. Without a long-term approach the measures needed for improving outcomes and delivering value for money cannot be taken. We recommend that, following consultation between the Department of Health, the HSC Trusts and the community and voluntary sectors to determine budget priorities, the UK Government work with the Department of Health and the Department of Finance to produce three-year minimum budget allocations. This should be implemented from the next budget.

## 2 Cancer services

#### **Cancer in Northern Ireland**

- 38. Cancer is the leading cause of death in Northern Ireland. Of the 16,036 deaths registered in Northern Ireland in 2017, 4,460 (27.8 per cent) were due to cancer. Over the last decade, incidences of cancer have increased 15.1 per cent (excluding non-melanoma skin cancer) from 8,269 cases in 2008 to 9,521 cases in 2017. This is mostly due to Northern Ireland's aging population—63 per cent of cases diagnosed occurred in people over the age of 65 years and incidence rates are highest for those aged 85–89 years. It has been estimated that by 2020, almost one in two will get cancer at some point in their lives.
- 39. The most common cancers diagnosed among males between 2013 and 2017 were prostate (1,133 cases on average per year), 82 lung (680 per year) and colorectal (652 per year) while the most common cancers among women were breast (1,398 on average per year), 85 lung (610 per year) and colorectal (532 per year). 87

Figure 4: Incidence of cancer in Northern Ireland, 1993-2017



Source: N. Ireland Cancer Registry, 2017 Cancer incidence, survival, mortality and prevalence data, 12 March 2019

- 78 Northern Ireland Statistics and Research Agency, <u>Registrar General Annual Report 2017 Cause of Death</u>, 7 November 2018
- 79 Queen's University Belfast, Cancer incidence and survival statistics for Northern Ireland 1993–2017, 12 March 2019, page 2
- 80 Ibid., page 1
- 81 Macmillan, Cancer mortality trends: 1992–2020, May 2013
- 82 N. Ireland Cancer Registry, Prostate Cancer, accessed 14 May 2019
- 83 N. Ireland Cancer Registry, Lung Cancer, accessed 14 May 2019
- N. Ireland Cancer Registry, Colorectal Cancer, accessed 14 May 2019
- 85 N. Ireland Cancer Registry, Breast Cancer, accessed 14 May 2019
- 86 N. Ireland Cancer Registry, <u>Lung Cancer</u>, accessed 14 May 2019
- 87 N. Ireland Cancer Registry, Colorectal Cancer, accessed 14 May 2019

- 40. The standardised incidence rate for cancer is 24 per cent higher in the most deprived communities than in the least deprived communities while premature mortality from cancer is 72 per cent higher in the most deprived communities than in the least deprived. This gap has remained broadly consistent over the last decade. Incidence rates by cancer type also vary between socioeconomic groups—breast cancer and melanoma tend to be more common in areas of low deprivation while lung, stomach, male-colorectal and cervical cancer are more prevalent in areas with high deprivation. 90
- 41. A patient's prospects are largely determined by the stage of progression at diagnosis—for example, 99 per cent survive breast cancer for 5 years or more when diagnosed at an early stage but this falls to 18 per cent when diagnosed at a late stage; 98 per cent survive bowel cancer when diagnosed at an early stage but this falls to 9 per cent when diagnosed at a late stage; and 44 per cent survive lung cancer when diagnosed at an early stage while only 2 per cent survive if diagnosed at a late stage. Timely diagnosis is therefore essential for a patient's survival prospects. However, a significant proportion of cases in Northern Ireland are diagnosed at a late stage—20 per cent are diagnosed at stage III and 26 per cent at stage IV. These numbers are even higher for men—21 per cent of men are diagnosed at stage III and 31 per cent are diagnosed at stage IV. Late diagnosis can be due to a number of factors, including low public awareness of signs and symptoms, hesitation or delay in seeing a GP or delays further in the diagnostic pathway.

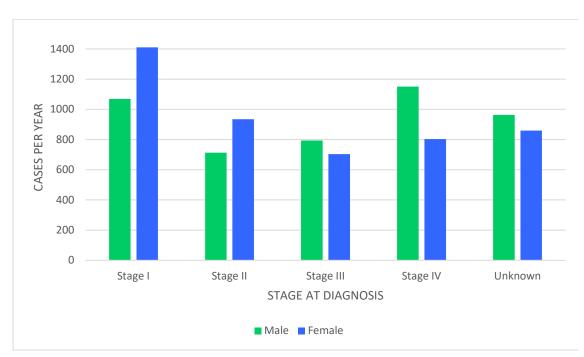


Figure 5: Stage of cancer at diagnosis, average number of cases per year, 2013–2017

Source: N. Ireland Cancer Registry, 2017 Cancer incidence, survival, mortality and prevalence data, 12 March 2019

- 88 Department of Health, Health inequalities annual report 2019, March 2019, page 21
- 89 Ibid., page 19
- 90 N. Ireland Cancer Registry, Cancer incidence and survival statistics for Northern Ireland 1993–2017, 12 March 2019
- 91 Queen's University Belfast, Release of the cancer incidence and survival statistics for Northern Ireland 2012–2017, 12 March 2019
- 92 N. Ireland Cancer Registry, 2017 Cancer incidence, survival, mortality and prevalence data, 12 March 2019
- 93 Ibid.

Despite this, advances in cancer care and treatment mean that more people are surviving cancer for longer. According to the most recent statistics one-year net survival for both sexes is 71 per cent and five-year net survival is 56 per cent. This compares with 63 per cent one-year survival and 45 per cent five-year survival a decade prior. Despite this, advances in cancer care and treatment mean that more people are survival for both sexes is 71 per cent and five-year net survival is 56 per cent. This compares with 63 per cent one-year survival and 45 per cent five-year survival a decade prior.

#### **Cancer waiting times**

- 42. Ministerial targets for cancer waiting times were set in 2009 and have not been amended since. These targets are:<sup>96</sup>
  - At least 95 per cent of patients urgently referred with a suspect cancer should begin their treatment within 62 days;
  - At least 98 per cent of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat;
  - All urgent breast cancer referrals should be seen within 14 days.

The Department of Health reports on performance against these targets on a quarterly basis. Records show a gradual deterioration in performance against these targets. The 62 day target has never been met since its introduction; the 31 day target has not been met since December 2013; and the 14 day breast cancer target has not been met since March 2018 (though close to target levels were reached in April, November and December 2018).<sup>97</sup>

43. In addition to these targets not being met, the targets themselves do not capture the full extent of the patient pathway—none of the targets include time spent waiting for a GP appointment; the 31 day target does not capture the waiting time from referral to treatment; and the 14 day target only applies to breast cancer. The total waiting time for patients is therefore likely to be longer than what is captured by these targets. Cancer Focus Northern Ireland told us that:<sup>98</sup>

It really starts [ ... ] with pressure on our GP services where people may have a symptom they are concerned about, [ ... ] they try to see their GP, and it is three weeks before they see their own GP. There is where your first delay starts. [ ... ] Routinely, if you go to a GP now in Northern Ireland, not a red flag referral necessarily but if there are symptoms that might be cancer, you will be asked, "Can you afford to go privately for an MRI or a CT scan?" If you can, it does relieve pressure on the health service but off you go and you get your scan within three or four days. If you do not have that money—and a lot of people do not—then you are into very long waits.

The point that patients are having to resort to funding their own care to avoid long waits was made to us by Melanie Kennedy, who was diagnosed with breast cancer in 2014:<sup>99</sup>

<sup>94</sup> Ibid.

<sup>95</sup> Ibid

<sup>96</sup> Dr Lesley-Ann Black and Keara McKay, Cancer: Northern Ireland, 28 June 2017, page 21

<sup>97</sup> Ibid., pp. 22–24; Department of Health, Northern Ireland Waiting Time Statistics: Cancer Waiting Times
January—March 2019, 28 March 2019, page 5

<sup>98 &</sup>lt;u>Q60</u>

<sup>99</sup> Q154

An alarming amount of people are relying on crowd funding and selffunding to get appointments quicker, to get treatments quicker. It is fast becoming a two-tier system. I am a believer in the NHS and it is something I am very, very reluctant to see and I would say it is happening a lot faster than it is in other parts of the UK because of our circumstances.

Waiting for extended periods of time for a diagnosis or treatment can cause significant distress for those made to wait. Melanie Kennedy went on to tell us that:<sup>100</sup>

People are having scans very, very late. They are not timely enough and they are not being read, and people are waiting a long time for results, which [ ... ] impacts mental health for cancer patients. I believe [ ... ] that physical and mental health are intrinsically linked, so this cannot be good for anybody—sitting and waiting around for something that could be a life-changing scan result, and you are living in limbo waiting on it.

44. The Committee heard that the Department's failure to meet its Ministerial targets is linked with a high number of unfilled posts in the workforce. Cancer Research UK told us that:<sup>101</sup>

Poor performance against cancer waiting time targets [ ... ] demonstrates acute pressures in the HSC workforce, with workforce shortages creating delays in the diagnostic pathway. [ ... ] A wide variety of staff is required to deliver cancer services encompassing prevention, diagnosis, treatment and care, so staff shortages across the Health and Social Care system impact cancer services at all levels.

The point was also put to us by Prostate Cancer UK:102

It is not always about having the equipment or paying an initial outlay to have [...] new scanning equipment. Often the equipment is there but does the hospital or the trust have the capacity to get those scans done? Is the workforce there? Can they cope with the workload with the current workforce they have? At the moment, it is clear to see that they can't.

45. According to the most recent workforce census by the Royal College of Radiologists, while there has been steady growth in the number of consultant clinical radiologists in England over the past four years there has been no significant increase in Northern Ireland. <sup>103</sup> Northern Ireland has the highest vacancy rate for consultant clinical radiologist posts in the United Kingdom at 18 per cent. This compares with 10 per cent in Wales (the second highest) and 9 per cent in England. <sup>104</sup> The Royal College's census on the clinical oncology workforce estimated a similar shortfall in the number of consultant clinical oncologists of 16 per cent, or approximately six whole-time equivalent posts. <sup>105</sup> This would require an additional eight trainees to account for rates of attrition in specialty training and less-

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    100 Q146
    101 Cancer Research UK (HTH0017)
    102 Q72
    103 The Royal College of Radiologists, Clinical radiology UK workforce census 2018 report, 5 September 2018, page 12
    104 Ibid., page 19
    105 The Royal College of Radiologists, Clinical oncology Northern Ireland workforce census report 2018, 1 July 2019, page 3
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than-full-time working.<sup>106</sup> However, an average of only two doctors per year in Northern Ireland enrol on specialist training for clinical oncology.<sup>107</sup> To address this shortfall the number would need to double over the next four years.<sup>108</sup> The census also found that most consultant clinical oncologists were working extended hours to help cover for workforce shortages with almost half contracted to work over 48 hours per week and many taking on additional unpaid overtime.<sup>109</sup>

46. The disparity in unfilled vacancies between Northern Ireland and elsewhere in the United Kingdom has been linked to disparities in pay. The British Medical Association told us that:<sup>110</sup>

The lack of investment in the permanent workforce means that working in Northern Ireland is not seen as an attractive option. For example, recent pay uplift recommendations from the DDRB [Review Body on Doctors' and Dentists' Remuneration] are not certain to be introduced in Northern Ireland, due to the lack of a health minister. Additionally, the failure to run clinical excellence rounds since 2010 has contributed to a reduction in consultant salaries, especially when compared to their colleagues in other UK jurisdictions.

A recent workforce analysis by Cancer Research UK also identified regional disparities in the ability to recruit, quoting a lead clinician as saying:<sup>111</sup>

The Belfast area tends to be protected as that's where people go to university, to settle and live. Other Trusts have different challenges around recruitment. Regionally in Northern Ireland we seem to have shortages of oncologists, shortages of haematologists and shortages of radiologists.

- 47. When asked by this Committee what steps were being taken to bring down waiting times, the Department cited the following measures:<sup>112</sup>
  - Director level cancer performance meetings held between the HSC Board and HSC Trusts to seek assurances from the Trusts that the longest waiting patients are treated, with a continued focus on ensuring that, where treatment does not commence within 62 days, no patient is left waiting longer than 85 days.
  - The Strategic Framework for Imaging Services, published in June 2018, which aims to enhance and modernise the HSC's imaging services over the next ten years together with year on year increases in radiology trainees and ongoing work to optimise skill mix opportunities within imaging teams.
  - The review of oncology services being taken forward by the Northern Ireland Cancer Network which will produce recommendations on the improvement of treatment pathways (subject to Ministerial approval).

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106 Ibid., page 6
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<sup>107</sup> Ibid., page 6

<sup>108</sup> Ibid., page 6

<sup>109</sup> Ibid., page 3

<sup>110</sup> BMA Northern Ireland (HTH0018)

<sup>111</sup> Cancer Research UK, Where next for cancer services in Northern Ireland?, September 2016, pp. 51–52

<sup>112</sup> Correspondence from the Permanent Secretary of the Department of Health, 20 November 2018

- The review of the Breast Cancer Assessment Service for patients referred with suspect cancer which recommends service reconfiguration and consolidation on fewer sites (subject to public consultation).
- The ten-year workforce strategy as set out in *Delivering For Our People*.
- 48. While the Committee welcome these measures, there continues to be a lack of focused workforce planning specifically to fill those vacancies that are leading to delays for patients. We were told by the Department that "the national shortage of radiologists cannot be alleviated in the short term and work will continue to explore a range of approaches to address this problem." However, it is unclear what further measures have been taken by the Department.
- 49. The Committee heard of a number of innovative solutions to workforce shortages. These included: fast-tracking remote monitoring and interpretation of scans by radiologists based outside Northern Ireland;<sup>114</sup> the use of artificial intelligence to support radiography and pathology;<sup>115</sup> and greater north-south cooperation on the island of Ireland.<sup>116</sup> Innovative approaches will be essential for mitigating chronic shortfalls in critical staff. However, it is doubtful whether these will be sufficient to bring waiting times down to target levels without a concurrent strategy for recruiting and retaining an adequate workforce.
- 50. Cancer incidence increases with age and demand for cancer services is likely to rise as Northern Ireland's population ages. To meet this demand in the long-term a reconfiguration of services under the direction of an overarching strategy will be essential. However, in the medium-term action is needed to slow and ultimately reverse the upward trend in waiting times. The Committee recommends that the Department of Health commit to a baseline assessment to identify where gaps in the HSC workforce are contributing to delays in the diagnostic pathway for cancer patients. The Department should subsequently bring forward a strategy for closing those gaps through the recruitment and retention of an adequate workforce alongside innovations in technology and service delivery, to be published in draft by summer 2020.

#### **Cancer strategy**

51. The World Health Organisation recommends a national cancer control programme that is "goal-oriented, realistic, carefully prepared and appropriately funded through a participatory process" to reduce the cancer burden and improve quality of life for cancer patients "no matter what resource constraints a country faces." However, while England, <sup>118</sup> Scotland <sup>119</sup> and Wales <sup>120</sup> each have updated cancer strategies in place, Northern Ireland's cancer strategy has not been updated since 2008. <sup>121</sup>

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Correspondence from the Permanent Secretary of the Department of Health NI, to the Chair, regarding cancer services in Northern Ireland, 20 November 2018
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<sup>114 073</sup> 

<sup>115</sup> Q83

<sup>116</sup> Q73

<sup>117</sup> World Health Organization, National Cancer Control Programmes (NCCP), accessed 3 June 2019

<sup>118</sup> Achieving world-class cancer outcomes: A strategy for England 2015–2020, accessed 3 June 2019

<sup>119</sup> Beating cancer: ambition and action, accessed 3 June 2019

<sup>120</sup> Cancer Delivery Plan for Wales 2016–2020, accessed 3 June 2019

Northern Ireland Assembly Research and Information Service, Cancer: Northern Ireland, Briefing Paper No. 32/17, 28 June 2017, page 7

- 52. The Committee heard unequivocal support for the development of a new cancer strategy for Northern Ireland. Cancer Focus NI told us that the increase in cancer cases would "only be tackled by developing and implementing a comprehensive and well-resourced cancer strategy for Northern Ireland." Macmillan and the Royal College of Nursing called for a "clear commitment" to developing a new strategy. Prostate Cancer UK told us that an updated cancer strategy was "imperative" and a "number one priority" which should aim at providing a comprehensive top-down analysis of cancer diagnosis, treatment and support in Northern Ireland to point out the nodes at which key investment can be made to improve the situation. Present Cancer Now told us that an "effective, overarching cancer strategy, sets direction, and would be crucial in helping with investment decisions and plans for the longer-term" and that up-to-date strategies had led to advances in treatment and care in England, Scotland and Wales. Prostate Cancer UK raised concern that in the absence of an up-to-date strategy cancer services in Northern Ireland would fall behind the rest of the United Kingdom.
- 53. The Committee heard that without a cancer strategy in place, long-term planning for cancer services was lacking. Cancer Research UK expressed concern that Confidence and Supply funds were not being deployed strategically in the absence of a joined-up strategy:<sup>130</sup>

There is an imaging review that is being funded by that money. There is a pathology modernisation project that is being funded by that money. There is a lot of work on general practice. There is a piece of work specific to cancer treatment on delivery of chemotherapy and radiotherapy. [ ... ] All those individual pieces are out there being thought about but there is no whole and there also is no long-term thinking. Part of the problem is that we are just putting sticking plasters on things and it results in a system that is inefficient. As soon as one thing gets fixed, something else breaks and you have to fix that. It is indicative of a system that needs a cancer strategy more than anything else, something that analyses all the issues [ ... ] from research through treatment, including workforce, research and data. [ ... ] We just do not do that.

Melanie Kennedy also described the current model as a "sticking plaster approach" and that focus was needed to develop "a long-term plan for the increasing amount of people who are going to be diagnosed." <sup>131</sup>

54. The Committee heard of a number of areas in which Northern Ireland was lagging behind the rest of the United Kingdom in the absence of a cancer strategy. Cancer Research UK told us that Northern Ireland had been "very slow" to run awareness campaigns, contrasting the Be Clear on Cancer<sup>132</sup> campaign currently running in England with the

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Cancer Focus Northern Ireland (HTH0015)
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     Macmillan Cancer Support (HTH0012); Royal College of Nursing (HTH0037)
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     Prostate Cancer UK (HTH0042)
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     Q82
     Prostate Cancer UK (HTH0042)
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127
     Breast Cancer Now (HTH0005)
128
     083
     Q73
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     Ibid.
131
     NHS, Be Clear on Cancer, accessed 14 August 2019
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lack of an awareness campaign in Northern Ireland for over two years.<sup>133</sup> Prostate Cancer UK similarly told us that "without a cancer strategy and that top-down direction, things are moving at a much slower pace."<sup>134</sup> Cancer Focus NI told us that Northern Ireland had been "very slow"<sup>135</sup> to adopt new systems for diagnosis and treatment and that Northern Ireland was now falling behind the rest of the United Kingdom, remarking that "it is that other people have become better rather than that we have become worse."<sup>136</sup> The Committee also heard criticism of the paucity of data on cancer in Northern Ireland, with calls to improve the scope, collection and sharing of data.<sup>137</sup> Cancer Research UK further highlighted problems in the diagnostic system, telling us that a lot of work was needed on:<sup>138</sup>

Cohesion, better screening programmes, better awareness, organising diagnostic testing, locations, workforce, and making sure we have enough kit [and] machines.

Breast Cancer Now pointed to opportunities to improve earlier diagnosis that had opened up under the direction of England's cancer strategy, citing the roll-out in England of 'onestop shops' for people with non-specific symptoms to break the cycle of multiple referrals and speed up diagnosis. <sup>139</sup>

- 55. We heard that, in line with the World Health Organisation's recommendation of a "participatory process," any new cancer strategy should be developed in collaboration with other Departments, Health and Social Care organisations, key stakeholders including the voluntary and community sectors, and guided by the expertise of healthcare professionals and the voice of patients. <sup>140</sup> We were also provided by Cancer Research UK with a detailed summary of those areas that any new cancer strategy should cover, informed by an evaluation of cancer services in Northern Ireland conducted in 2016. <sup>141</sup> These included: <sup>142</sup>
  - a strong focus on the prevention of modifiable cancer risk factors such as smoking, obesity, and alcohol—in particular, funding programmes that target communities which experience social deprivation where these risk factors are more prevalent;
  - a commitment to work with other UK public health agencies and the Republic of Ireland on improving diet and reducing obesity;
  - improving early diagnosis;
  - the development of a centralised initiative which coordinates all efforts to diagnose cancers at an earlier stage including: the development of multidisciplinary diagnostic centres; direct GP access to diagnostic tests; ensuring the availability of diagnostic equipment; and addressing workforce shortages within diagnostic pathways;

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133
     Q63
     Q73
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     Q71
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     Ibid.
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     Q152; Cancer Research UK (HTH0017)
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     Q64; NHS England, New 'one stop shops' for cancer to speed up diagnosis and save lives, 3 April 2018
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140 Macmillan Cancer Support (HTH0012); Royal College of Nursing (HTH0037)
     Cancer Research UK, Where next for cancer services in Northern Ireland?, September 2016
    Cancer Research UK (HTH0017)
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- improving access to treatments;
- a plan for integrating research throughout the health and social care system in Northern Ireland to foster a culture of research at all levels, with the aim of at least 30 per cent of patients discussing taking part in cancer research by 2023;
- the collection and publication of more robust data, and a commitment to ensuring that data from the new Regional Information System for Oncology and Haematology (RISOH) can be used to monitor equitability and speed of uptake of new medicines across Northern Ireland:
- ensure a multi-year funding model rather than short-term project-based grants for the Northern Ireland Cancer Registry, to allow for a more strategic, longerterm approach;
- implementation of the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016.
- 56. On 7 March 2019, during the course of the inquiry, the Department of Health announced that a new cancer strategy for Northern Ireland would be commissioned. The Department stated that it had looked into the various arrangements that had supported the development of cancer strategies in neighbouring jurisdictions and saw merit in the model used by NHS England, whereby an Independent Cancer Taskforce had been established to work with professional cancer services staff, patients, cancer charities, commissioners, care providers and other key stakeholder groups. The Department has since set a completion date for a new strategy of June 2020.
- 57. The Department has stated that implementation of the new strategy "would be for a future Health Minister." While the Department told us that recent legislation had helped the Department to progress a new cancer strategy, there remained difficulties in funding its implementation in the absence of a Health Minister, as such decisions could result in cutbacks elsewhere: 147

The [Northern Ireland (Executive Formation and Exercise of Functions) Act 2018] has been extremely helpful both on this issue and on a range of issues in terms of our ability to take decisions. On the limitations—this is an issue we will come to when we develop the strategy—taking a decision to approve and implement a new cancer strategy in one sense is easy, in and of itself. The difficulties lie in how we fund that and, particularly, how we fund it within a finite budget. The reality is that, where additional costs would lie and go alongside the implementation of that strategy, a fixed budget will mean that activity elsewhere will have to be scaled back.

58. Northern Ireland is alone in the United Kingdom in not having an up-to-date cancer strategy. Without an integrated, long-term vision for improving cancer services under the direction of a well-conceived strategy, cancer services in Northern Ireland will struggle to keep pace with demand. As such, the Committee welcomes

<sup>143</sup> Department of Health, Department announces way forward on a new cancer strategy, 7 March 2019

<sup>144</sup> Ibid.

<sup>145</sup> Northern Ireland Executive, New strategy will help us meet cancer increase challenge, 10 May 2019

<sup>146</sup> Ibid.

<sup>147</sup> Q314

the Department's announcement that a new cancer strategy for Northern Ireland is in development. However, we recognise that many will be concerned that decisions on a new strategy are awaiting Ministerial approval. We recommend that the Department set out, in response to this report, clear timescales for its programme of work in developing a new cancer strategy and provide regular updates on progress made. This timescale should set out the key milestones where Ministerial decisions should be made.

#### Access to cancer treatments

- 59. The National Institute for Health and Care Excellence (NICE) is responsible for providing the NHS with advice on effective and good value healthcare. The Institute produces technology appraisals guidance which assess the clinical and cost effectiveness of health technologies, including pharmaceutical and biopharmaceutical products, procedures, devices and diagnostic agents, to help ensure that the NHS is able to adopt new developments quickly and consistently.<sup>148</sup>
- 60. NICE aim to issue final guidance on all new treatments within 90 days of the treatment being licensed. The NHS is then legally obliged to fund and resource treatments appraised by NICE within three months of the date of appraisal. The appraisal process results in one of three recommendations: 151
  - recommended for routine commissioning;
  - not recommended for routine commissioning; or
  - recommended for use within the Cancer Drugs Fund.

Drugs are recommended for use within the Cancer Drugs Fund where NICE consider there to be plausible potential for a drug to meet the criteria for routine commissioning but where significant clinical uncertainty remains.<sup>152</sup>

61. Until recently, Northern Ireland was alone in the United Kingdom in lacking a mechanism for patients to access innovative new treatments that would be available through the Cancer Drugs Fund. The only option for patients in Northern Ireland to access a particular treatment that had not been recommended for routine commissioning by NICE was for their hospital consultant to submit an Individual Funding Request (IFR) to the Health and Social Care Board on their behalf. In order for the Health and Social Care Board to approve an IFR, the application had to demonstrate that there were "exceptional clinical circumstances" on the grounds that "the patient is significantly different to the general population of patients with the condition in question." This was defined as "an individual whose clinical circumstances are outside the range of clinical circumstances presented by at least 95 per cent of patients with the same medical condition at the same stage of progression as the named patient."

<sup>148</sup> National Institute for Health and Care Excellence, What we do, accessed 31 August 2019

<sup>149</sup> NHS England, Appraisal and Funding of Cancer Drugs from July 2016 (including the new Cancer Drugs Fund), 8
July 2016, page 6

<sup>150</sup> National Institute for Health and Care Excellence, NICE technology appraisal guidance, accessed 31 August 2019

<sup>151</sup> Ibid

<sup>152</sup> Ibid.

<sup>153</sup> HSC Business Services Organisation, HSCB arrangements for the consideration of requests for care and/or treatment on behalf of individual patients, page 2

<sup>154</sup> Ibid., pp. 7–8

- 62. The consequence of this was that drugs made available elsewhere in the United Kingdom were not made available to patients in Northern Ireland without extended delays, of years in some cases, if at all. We heard that clinicians were reluctant to submit IFRs for their patients due to the strict exceptionality criteria and many patients had to resort to funding their own treatment or lobbying to access the treatments they needed. Northern Ireland was also unable to benefit from managed access agreements for CDF medicines, which resulted in significantly higher costs per patient for those who were approved.
- 63. Beyond the immediate impact on patients, we also heard that this would make Northern Ireland a less attractive place to conduct clinical trials.<sup>157</sup> This in turn would make it more difficult to attract specialist clinicians to work in Northern Ireland.<sup>158</sup> The pharmaceutical company Bristol Myers-Squibb described the range of wider benefits that clinical trials bring to the region, which consequently were at risk:<sup>159</sup>

It allows some patients to receive a potentially life-extending treatment, providing access prior to the medicine gaining market authorisation. There are also financial benefits for the health service from research investment, as well as cost savings due to pharmaceuticals being provided for free. In addition there are a number of wider positive benefits including benefits to infrastructure, the learning and skill development of clinicians, improved quality of care and health outcomes for patients as well as quicker uptake of new treatments.

- 64. During the course of the inquiry the Department of Health announced that it would be improving access to new medicines for cancers and other conditions. The changes included:<sup>160</sup>
  - Where NICE recommends new drugs for use within the Cancer Drugs Fund in England, these will now be made available in the same way as those drugs which have been recommended by NICE as suitable for routine commissioning.
  - The IFR process will cover licensed medicines that NICE has not recommended or has not yet appraised. Decisions on IFRs will be taken by a clinically led Regional Scrutiny Committee.
  - Consultants will be able to make decisions on the most appropriate treatments for patients and to make individual funding requests as clinically indicated to the Regional Scrutiny Committee.

The Department aimed to implement the changes within the financial year and estimated that the additional cost to the Department would be between £2 million and £2.5 million per annum.<sup>161</sup>

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AbbVie (<u>HTH0011</u>); Bowel Cancer UK (<u>HTH0047</u>); Bristol-Myers Squibb (<u>HTH0030</u>); Northern Ireland Assembly All-Party Group on Cancer (HTH0016); Prostate Cancer UK (HTH0042)
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<sup>156</sup> Association of the British Pharmaceutical Industry (HTH0024)

Association of the British Pharmaceutical Industry (HTH0024); Bristol-Myers Squibb (HTH0030); Cancer Focus Northern Ireland (HTH0015); Cancer Research UK (HTH0017); Northern Ireland Assembly All-Party Group on Cancer (HTH0016); Q143

<sup>158</sup> Bristol-Myers Squibb (<u>HTH0030</u>)

<sup>159</sup> Ibid.

<sup>160</sup> Department of Health, Department Announces Improved Access to New Drugs, 12 September 2018

<sup>161</sup> Ibid.

- 65. The Committee wrote to the Department in October 2018 to ask when patients could expect to benefit from these changes. In its reply, the Department told us that in order to ensure value for money they had asked the Regional Pharmaceutical Procurement Service to confirm the details of each commercial managed access agreement with the pharmaceutical companies. The Committee was told that discussions had commenced in mid-October and once confirmed, patients who were considered suitable by their clinical consultant would be able to access the new medicines. Until then, clinical consultants were accessing medicines on a cost per case basis, which meant that patients who were unable to apply for an IFR due to the issue of patient cohorts could now access CDF medicines.
- 66. The Department stated that the 95 per cent exceptionality clause would be removed and replaced with a term whereby clinicians demonstrate that the patient is more likely to gain significant clinical benefit from the treatment than other patients with the same condition at the same stage. However, until the clinically led Regional Scrutiny Committee was up and running the current IFR panel would continue to make decisions on applications, though augmented with additional, independent clinical input. A meeting with the newly constituted, clinically-led Regional Scrutiny Committee was scheduled for 23 November 2018 with the ambition that the committee would be considering applications from early 2019.<sup>166</sup>
- 67. In January 2019, we questioned the Permanent Secretary on the additional cost of implementing these changes. We were told that the initial uplift would be in the region of £500,000 which would increase to approximately £2 million recurrently. The Permanent Secretary told the Committee that: 168

Given previous ministerial commitments on this point, and there had been a lot of ministerial engagement, there is a pressing need to move the position. We need to move quickly to do that. I am confident that I can manage the costs, which are not that significant, within the churn as we move forward.

- 68. The Committee welcomes the Department's moves to place Northern Ireland on an equal footing with the rest of United Kingdom in opening up patient access to innovative new treatments. However, there has been a lack of updates on progress made towards realising the full raft of changes announced last year. The Department should update the Committee on what progress has been made so far and provide regular updates on further progress until such time as these changes are fully rolled out, or until the relevant Committee is constituted at Stormont.
- 69. In the course of our inquiry it was also brought to the attention of the Committee by several organisations<sup>169</sup> that Northern Ireland was lagging behind other UK jurisdictions in not committing to adopt screening methods recommended by the UK National

<sup>162</sup> Correspondence from the Chair to the Permanent Secretary of the Department of Health NI regarding cancer services in Northern Ireland, 24 October 2018

<sup>163</sup> Correspondence from the Permanent Secretary of the Department of Health NI, to the Chair, regarding cancer services in Northern Ireland, 20 November 2018

<sup>164</sup> Ibid.

<sup>165</sup> Ibid.

<sup>166</sup> Ibid.

<sup>167</sup> Q319

<sup>168</sup> Q317

<sup>169</sup> Bowel Cancer UK (HTH0047); Cancer Research UK (HTH0017)

Screening Committee, in particular the Faecal Immunochemical Test (FIT) offered to men and women aged 50 to 74 years to screen for bowel cancer<sup>170</sup> and tests for Human Papillomavirus (HPV) as the primary test in cervical screening.<sup>171</sup> Northern Ireland instead offers the less cost-effective Faecal Occult Blood Test (FOBT) to men and women aged 60 to 74 years<sup>172</sup> and routine smear tests as the primary test in cervical screening.<sup>173</sup>

70. In October 2018 the Committee wrote to the Permanent Secretary to ask the Department to commit to adopting more efficient methods.<sup>174</sup> The Department replied that, with respect to FIT, adopting the screening method would require:<sup>175</sup>

Reviewing patient pathways, drafting a procurement specification for the new test kits, analysing potential issues for colonoscopy capacity, looking at the requirements for a new IT module for the Bowel Screening Information Management System and revising patient and professional information.

The Department also stated that the greatest health gains would be made by rolling out the screening method to people aged 60 or over but that "extending the age range to 50 years remains an option to be considered." <sup>176</sup>

- 71. In January the Committee questioned the Permanent Secretary again on the adoption of FIT. We were told that the issue had been looked into in further detail and preparatory work was now underway. However, the Permanent Secretary wished to "defer the actual decision-making process until we get a budget allocation for 2019–20 and we can consider the financial implications." <sup>177</sup>
- 72. In April 2019 the Department announced that, having reviewed the Department's budget allocation, FIT would be adopted as the primary screening test for bowel cancer, to be introduced from early 2020. However, the announcement made clear that this would be offered to men and women participating in the Northern Ireland Bowel Screening Programme, which is offered to men and women aged 60–74. This does not extend the age range to 50 years as recommended by the UK National Screening Committee.
- 73. The Committee welcome the Department's announcement that FIT will be adopted as the primary screening test for bowel cancer. However, we are concerned that this will not be extended to men and women aged 50 and over as recommended by the UK National Screening Committee. We are not clear why this decision was made. The Committee recommends that the Department consider extending the programme to men and women aged 50 and over.

<sup>170</sup> Public Health England, Current UK NSC recommendations, Bowel Cancer, accessed 2 September 2019

<sup>171</sup> Public Health England, Current UK NSC recommendations, Cervical Cancer, accessed 2 September 2019

<sup>172</sup> Public Health Agency, Overview of the NI Bowel Cancer Screening Programme, accessed 2 September 2019

<sup>173</sup> Public Health Agency, Overview of Cervical Screening Programme, accessed 2 September 2019

<sup>174</sup> Correspondence from the Chair to the Permanent Secretary of the Department of Health NI regarding cancer services in Northern Ireland, 24 October 2018

<sup>175</sup> Correspondence from the Permanent Secretary of the Department of Health NI, to the Chair, regarding cancer services in Northern Ireland, 20 November 2018

<sup>176</sup> Ibid

<sup>177</sup> Q316

<sup>178</sup> Department of Health, The Department of Health is today making two significant health protection announcements, 8 April 2019

<sup>179</sup> Ibid.

- 32
- 74. With respect to tests for HPV as the primary test in cervical screening, the Department told the Committee that the introduction of primary HPV testing was expected to increase demand on colposcopy services, citing the 60 per cent increase in colposcopy referrals in England since introducing primary HPV testing. As a result, they told us that the Public Health Agency was leading work on exploring the impact of HPV testing on cervical screening and developing the optimum implementation strategy for managing demand. 180
- 75. The Committee welcome ongoing work to explore a managed strategy for introducing HPV testing as the primary test in cervical screening. However, there has been a lack of updates on progress made since the Committee questioned the Department in January. The Department should update the Committee on what progress has been made so far and provide regular updates on further progress until such time as primary HPV testing is rolled out fully, or until the relevant Committee is constituted at Stormont.

### 3 Social care

#### Social care in Northern Ireland

- 76. Health and Social Care have been structurally integrated in Northern Ireland since 1973, which makes it distinct from health systems in England, Scotland and Wales. The integration of health and social care is now widely seen as a desirable model among policy makers as the health and social needs of communities are often inter-related and integration allows for better coordination and continuity of services.
- 77. Social services encompass a range of personal care and practical assistance for children, young people and adults who require extra support. It includes support for the elderly, support for those with learning and physical disabilities, support for people with mental health needs, the homeless, people with substance abuse problems, victims of domestic abuse, child protection and end-of-life care. 'Social work,' which is a qualified and registered profession operating within legal frameworks to protect and support vulnerable people, is distinct from what is commonly referred to as social 'care' work, which does not generally require a formal qualification and deals with more direct, personal care to support vulnerable individuals with daily tasks and to engage with their community.
- 78. A significant amount of social care is provided by the private and voluntary sectors. According to the Department's workforce strategy, there are approximately 31,000 registered social carers in Northern Ireland, including 12,000 domiciliary care workers. It estimated that 75 per cent of these were employed in the independent sector, with 25 per cent employed by HSC Trusts. A recent survey found that, out of 870 sites providing over 1,000 adult social care services, 51 per cent were privately run with a further 24 per cent run by voluntary providers.<sup>181</sup>
- 79. The *Bengoa* report called for greater "depth" in the integration of health and social care in Northern Ireland, stating that "the benefits of integration have not been fully exploited" and that this would "require a great deal more work on how the system plans, funds and purchases care across acute care, general practice and community health, and social care provided by statutory, independent and community, voluntary and charitable providers." \*Bengoa\* envisaged a central role for social care in a transformed health service, highlighting its importance in preventing people from being admitted to hospital and subsequently facilitating their discharge when medically fit. \*The report further acknowledged that securing investment in social services had been difficult when faced with competing demands for healthcare investment but that there was a strong economic case for meeting social needs as unmet needs were associated with higher rates of emergency care, hospital admissions and readmissions, along with being linked to a number of costly health conditions including heart disease, mental disorders, diabetes and hypertension. \*Is4\*
- 80. The recent review of adult social care highlighted the broad and dynamic reach of social care, with overlaps in housing, education, work, leisure, transport and criminal justice

<sup>181</sup> Skills for Care and Development, The Economic Value of the Adult Social Care sector—Northern Ireland, 5 June 2018, page 5

<sup>182</sup> Systems, Not Structures: Changing Health and Social Care, 25 October 2016, pp. 45–46

<sup>183</sup> Ibid., page 20

<sup>184</sup> Ibid., page 46

services, stating that "it is vital that adult social care is acknowledged to be multifaceted, subject to and benefitting from multidisciplinary partnerships and relationships." It further emphasised the value of social care, stating that "social care should be recognised as a vital and positive part of the infrastructure of society and the economy." <sup>186</sup>

#### The social care workforce

81. Tasked with identifying key areas for reform in adult social care, an expert panel was established in December 2016 as part of the Department's Reform of Adult Care and Support project. The panel's report was published in December 2017 as *Power to People* (2017). Among its findings was that although "care work is highly skilled" care workers "receive amongst the lowest wages in the labour market, typically the minimum wage." <sup>187</sup> In addition: <sup>188</sup>

In the public sector, wages (and conditions) for care work are fairer, whilst in the private and voluntary sector, pay is often at minimum wage rates and service conditions have been eroded. Given that the majority of paid care work is now provided in the private and voluntary sector, there is clearly an imbalance. It also makes the divide between social care (largely provided by the independent sector) and health care (largely provided in the public sector) uneven in ways which can undermine career development and stability. It also hinders attempts at effective integration as the gulf in perceived value is so stark.

The outsourcing of care to the independent sector had led, according to the panel, to competition between providers based "almost exclusively on price" and consequently a "race to the bottom" as "by far the largest cost for any care provider is the cost of staff." <sup>189</sup>

82. The Health and Social Care workforce strategy, published in May 2018, shared these findings. According to the strategy, social care services were "reliant on the independent sector for the delivery of effective and efficient social care." The report noted that: 191

There can be considerable differences between the terms and conditions of employment for social care workers in statutory organisations and those employed within the independent sector. Lower pay, less favourable conditions, temporary or zero hours contracts and a perceived lack of recognition of their value to society, have all contributed to low morale and a high turnover of the workforce.

It further stated that "investment in learning and improvement for social care workers tends to be more limited in the independent sector." <sup>192</sup>

83. The Royal College of Nursing told us that "the relationship between the HSC and the independent sector (and particularly the financial dimension to it) is in urgent need

of re-examination and reappraisal,"<sup>193</sup> claiming that the independent sector was unable to compete with the HSC in the supply of appropriately skilled and experienced staff. <sup>194</sup> Age NI told us that it was "vital" that the role of community and voluntary organisations was recognised and that services should be provided by "a skilled, competent and valued workforce, with decent salaries, stable working conditions and manageable workloads," along with opportunities for continuous learning and improvement. <sup>195</sup>

- 84. The difficulties in recruiting and retaining social care workers were further explored in the Northern Ireland Social Care Council's workforce review *Social Care Matters* (2017). The review noted that a major challenge in responding to instability in the workforce was the lack of comprehensive data on social care which impeded workforce planning at a system-wide level. The NISCC argued that it was "important to invest in a regionally agreed and maintained set of workforce and sector data which will properly inform future social care workforce strategy and policy." The review agreed that due to competition with other low wage sectors social care needed to "demonstrate that it is an attractive and worthwhile career choice" but was currently falling short in its offer of poor wages, terms and conditions of employment and recognised career pathways to potential employees. <sup>197</sup> It recommended continued development of a competent social care workforce through core training, continuous professional development and opportunities for training and qualification which would open up career pathways to higher level roles within social care. <sup>198</sup>
- 85. The Cedar Foundation, a charity supporting people living with disability, autism and brain injury, told us that "the competitive pressures with other sectors of the economy, principally retail and hospitality, is presenting unsustainable pressures on the recruitment and retention of this workforce." They added that "all providers are now increasingly having to access short-term agency staff which is placing additional cost pressures upon the system, potentially undermining the quality of care that is being delivered." The Cedar Foundation also highlighted the problem of high levels of turnaround or 'churn' within the workforce, whereby workers move between employers or within organisations taking their skills and experience with them. This has meant that "there are fewer new entrants into the workforce" and that "internal movement is driven by nominal differences in pay rates. In effect the workforce quantum remains the same, costs increase for the new employer to achieve marginal gain [and] the previous employer faces voids and increased costs due to agency use to cover care commitments."
- 86. Marie Curie, a charity which provides care and support to people with terminal illnesses, told us that care providers had been unable to secure the staff needed to fulfil domiciliary care packages, contributing to delayed hospital discharge for patients across the health service.<sup>201</sup> They said that "challenges in attracting and retaining staff, owing largely

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193 Royal College of Nursing (HTH0037)
194 Ibid.
195 Age NI (HTH0048)
196 Northern Ireland Social Care Council, Social Care Matters, October 2017, page 21
197 Ibid., page 21
198 Ibid., page 22
199 The Cedar Foundation (HTH0004)
200 Ibid.
201 Marie Curie (HTH0051)
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to low pay, lack of professional status, poor conditions and inadequate opportunities for career development and progression" had created "a destabilising churn and shortage in the workforce, with providers unable to secure the staff needed to fulfil packages of care." <sup>202</sup>

87. The Committee heard from a number of independent providers and others that the disparity in conditions and wages between the independent and statutory sectors was having a negative impact on the provider network. The Cedar Foundation criticised the role of the Health and Social Care Trusts in making "superior and inequitable" offerings which, due to the dual role of Trusts in both the commissioning and provision of services were "in effect distorting the social care employment market while failing to support the provider network."<sup>203</sup> These criticisms were shared by the Compass Advocacy Network (CAN), a charity which offers training opportunities for adults with learning disabilities, autism and mental health issues, who told us that:<sup>204</sup>

Evidence has proven [ ... ] that voluntary and private organisations provide a more cost-effective social care service and 74 per cent of social care registered providers fall within these sectors. Yet salaries, terms and conditions offered by the statutory sector, or outside of social care, make employment within a Trust, or in other sectors, a more appealable option. Voluntary and private organisations are investing in the professional development of the workforce, only to risk losing them to a Trust. Not only is this costly and frustrating for the private and voluntary sector, but further impacts negatively on the sector collaborating to address the workforce pipeline challenge.<sup>205</sup>

88. Inspire also told us about losing staff to the Trusts after having invested in professional development:<sup>206</sup>

We have young people who come to us as their first career. They will be recruited by us, go through training, get maybe a couple of years experience and then almost invariably go into the local health trust for a job because they are better paid and have better pensions. We have done all the training. We have given them the experience, but it is really hard for us to hold on to them because we cannot match what the trust does.

89. Some of the difficulties faced by independent providers when competing with the statutory sector were outlined by CAN. They pointed to the regulatory burden on independent social care providers and the financial pressure this has put them under, including areas such as safeguarding, health and safety and GDPR, citing substantial investment in "resource, technology and management information systems to cope with this increased regulation." According to CAN, independent providers had come under increased financial pressure through budget freezes representing an equivalent real terms cut in excess of 20 per cent; the introduction of pension auto-enrolment which was not accounted for when budgets were originally set; and the introduction of the National Living Wage in April 2016 which accounted for the single largest overhead—at over 80 per cent of overall budgets. The consequence of annual uplifts in the National Living Wage

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202 Ibid.
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<sup>203</sup> Ibid.

<sup>204</sup> Compass Advocacy Network (HTH0003)

<sup>205</sup> Compass Advocacy Network (HTH0003)

<sup>206</sup> Q277

had led, according to CAN, to an inability to provide uplifts for staff in more responsible positions. CAN ultimately argued that "what are deemed statutory services tend to be subsidised by us, as a voluntary provider." <sup>207</sup>

90. The independent social care sector is struggling with competition from the low wage sector, particularly hospitality and retail, and a competitive relationship with the statutory sector. High quality social care requires a skilled and valued workforce but social care workers are often on low wages and have little scope for career development and progression. Action must be taken to make social care an attractive career choice and create closer parity between the independent and statutory sectors. The Committee recommends that the Department conduct a review of social care roles across the board to identify inconsistencies in roles, responsibilities and salaries as a step towards consolidation of the social care workforce. This review should be completed by summer 2020. The Department should further set out what steps are being taken to progress the proposals set out in Power to People for equalising pay and conditions across the social care workforce in response to this report.

#### Short-termism

- 91. In common with other areas of healthcare, social care has been impacted negatively by short-term budgets. The Northern Ireland Council for Voluntary Action told us that this had impacted particularly on the community and voluntary sectors, with year-on-year uncertainty impeding organisations' ability to retain staff and sustain services. Age NI told the Committee that community and voluntary providers were at the forefront of prevention and early prevention and that it was vital that effective planning was in place to maintain funding for these providers or to identify alternative service options should funding come to an end. 209
- 92. Marie Curie told us that "short-term budgets propped up by non-recurrent, in-year funding is not working"<sup>210</sup> and remarked that a short-sighted approach to budgeting had led to counter-strategic decisions, giving the example of in-year savings measures in 2017 leading to cuts that were ultimately reversed:<sup>211</sup>

Funding shortages meant local health trusts had to consult on in-year saving measures. Many of the proposals put forward, including cuts to domiciliary care, Self Directed Support and nursing home places, were entirely counterstrategic and were reversed after significant public pressure. We would be concerned about this process being repeated—the saving plans did nothing to resolve the long-term and strategic problems facing the health service and only succeeded in causing unnecessary anxiety among patients and service providers, as well as damaging public trust in health decision-makers.

93. Marie Curie also linked the problem of delayed hospital discharge to a lack of long-term strategic planning. Data secured from Freedom of Information requests by Marie Curie showed that in 2017–18 there were 46,148 delayed bed days across the health service due to delayed discharge, averaging at more than 3,800 delayed days a month,

<sup>207</sup> Ibid

<sup>208</sup> Northern Ireland Council for Voluntary Action (HTH0038)

<sup>209</sup> Age NI (HTH0048)

<sup>210</sup> Marie Curie (HTH0051)

<sup>211</sup> Marie Curie Northern Ireland (HTH0026)

mainly due to a lack of domiciliary care packages and a shortage of available care home beds. <sup>212</sup> 204 patients died while waiting to be discharged from hospital during 2017–18. <sup>213</sup> Marie Curie claimed that in the face of rising demand and budgetary shortfalls, existing structures could not cope and that, along with investment in the workforce, a range of funding measures for social care should be looked into with "a move away from short-term financial planning, in favour of longer-term budget setting, so that services can be commissioned and planned in a more strategic way." <sup>214</sup>

94. We also heard that short-term contracts were a problem for many providers. Barnardo's Northern Ireland told us that short-term contracts restricted innovation and learning, given that a proportion of this period was spent on 'bedding in' at the beginning and preparing to re-tender at the end. Barnardo's Northern Ireland advocated long-term partnerships of at least five years in place of short-term contracts to deliver a range of improved outcomes:<sup>215</sup>

With longer contracts, voluntary organisations like Barnardo's can provide meaningful support and effective interventions, whilst also developing sustainability of the service. This sustainability allows innovation and learning, as well as strategic planning to promote better outcomes. We recommend that short-term contracts are replaced with a longer-term strategic partnerships model, in line with an outcomes-focused rather than task orientated approach to commissioning and strategic investment.

- 95. Action for Children similarly told us that "like other sectors, the voluntary and community sector needs to be able to plan ahead and often leads the way in finding innovative solutions, based on collaborative working" but that this required "more sustainable contract periods."<sup>216</sup>
- 96. Short-term budgets are having a particularly negative impact on social care, with year-on-year uncertainty impeding the ability of providers to plan for the future and develop service innovations. As we have recommended in paragraph 36, three-year minimum budget allocations are needed for the Department of Health. This should facilitate the Department moving towards a minimum five-year partnership model with community and voluntary providers in which commissioning and investment are based on progress towards agreed outcomes.

### **Bureaucracy**

97. The Committee heard that excessive bureaucracy was having a significant impact on social workers. The National Director of the British Association of Social Workers Northern Ireland told the Committee: "I cannot stress enough to this Committee the importance of the issue of bureaucracy to social workers" and that "any time we engage with social workers, the single biggest issue they talk to us about is bureaucracy and paperwork." <sup>218</sup>

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212 Marie Curie (HTH0051)
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<sup>213</sup> Ibid.

<sup>214</sup> Ibid.

<sup>215</sup> Barnardo's Northern Ireland (HTH0034)

<sup>216</sup> Action for Children (HTH0020)

<sup>217</sup> Q87

<sup>218</sup> Q101

98. A 2012 survey conducted by the Northern Ireland Association of Social Workers found that, of those surveyed:<sup>219</sup>

- 96 per cent highlighted report writing as a specific difficulty that impacts on their ability to spend time in face to face work with clients;
- 90 per cent highlighted recording in client files as a specific difficulty that impacts on their ability to spend time with clients;
- 73 per cent identified entering information into computer systems as impacting on the time they can spend directly with clients;
- 78 per cent spend less than a third of their working week in direct contact with clients.

99. In the same year the Department of Health, Social Services and Public Safety launched its 10-year strategy for social work in Northern Ireland—*Improving and Safeguarding Social Wellbeing*. Among its strategic priorities were to "improve employer supports for social workers in carrying out their work" which would require "employers to ensure social work time and skills are used to best effect" and a reduction in "unnecessary bureaucracy for social workers [ ... ] ensuring a healthy working environment with appropriate administrative and technological supports."<sup>220</sup>

100. A report published in 2018 on progress made against the 2012 strategy found that "while there have been a number of successful small-scale initiatives to address [social workers' time in direct practice], their impact on the wider system has been limited." We were told that, with respect to the strategy, "while there was great intent [ ... ] and a lot of effort, unfortunately, there has been a minimal impact, in terms of how much bureaucracy has been taken out of the system." <sup>222</sup>

101. The Committee heard that excessive time spent on paperwork represented a waste of social workers' skills and expertise. The British Association of Social Workers put it to us that:<sup>223</sup>

You have a social worker who is highly skilled, has gone through university, is skilled, trained and ready to do a job working with people. To expect them to spend 70 per cent of their working day and week filling out paper forms, duplicating those forms by putting them on to a computer system and inputting data is just unacceptable. We would not accept that of other professional jobs. We would not accept, for example, our GPs spending 70 per cent of their clinic time filling in a form. We should not accept it in social work.

102. We heard of a number of negative impacts on service users of excessive bureaucracy. We were told that it curtailed the opportunity for social workers to build productive relationships with service users and that the number one priority of service users was the

<sup>219</sup> Northern Ireland Association of Social Workers, Social Work Not Paperwork, November 2012, pp. 6–9

<sup>220</sup> Department of Health, Improving and Safeguarding Social Wellbeing, April 2012, pp. 13–14

<sup>221</sup> Department of Health, <u>Improving and Safeguarding Social Wellbeing: Stage 2 Progress Report</u>, December 2018, page 24

<sup>222</sup> Q89

<sup>223</sup> Q88

availability of their social worker.<sup>224</sup> The inability of social workers to visit, or of service users to get hold of their social worker on the phone, was a source of stress for many.<sup>225</sup> We were also warned that "you often hear the mantra, 'If it's not recorded, it didn't happen'" and that "there has been a sense of covering oneself that has grown up [ ... ] that has become an embedded culture now."<sup>226</sup> The British Association of Social Workers told us that:<sup>227</sup>

The response to practically every single inquiry where there has been a death or serious injury of a child, over the last two or three decades, has resulted in increased bureaucracy, so increased forms. There is a notion that having a piece of paper, having someone fill in a form and tick a box, or do an increasingly lengthy assessment, is the solution to that and we say it is not.

103. Despite these concerns, it was made clear to the Committee that good-quality recording and report writing were integral to good social work practice and that clear records were essential for governance and accountability.<sup>228</sup> However, the quantity and in some cases duplication of documentation was described to us as excessive and wasteful. The British Association of Social Workers gave the following description of the bureaucratic processes surrounding looked-after children:<sup>229</sup>

There are huge amounts of paperwork that start when a child becomes looked after, and rightly so. There should be good processes around documentation, but the documentation is excessive. Each child in a family, if there are six or 10 children, has to have this set of documents, 50-plus pages of documents, which are required at different points of time for review processes. Child protection processes often run at the same time. There is different documentation for the child protection process, and there is a UNOCINI [Understanding the Needs of Children in Northern Ireland assessment framework], which is a single assessment for children's services. All this different documentation runs at the same time. This is our question: why are there three different requirements for forms that all relate to the one child and assessing their needs? As a real example of that, for children who have a disability, if they require one night's respite care in a year, they automatically become looked-after children. That gives them a certain legal status. They are then required to become subject to the full looked-after process, so all the forms I am talking about have to be completed for that one child, for one night. It is unacceptable.

104. We were sent the forms associated with the assessment of need in adult social work services from a social worker employed in the Northern Health and Social Care Trust. The core Northern Ireland Single Assessment Tool (NISAT) ran to almost thirty pages and was associated with a further eleven forms involved in the assessment and support process. We were told that this did not include further paperwork associated with additional stages and that this was in addition to the requirement of social workers to keep

<sup>224</sup> Q88

<sup>225</sup> Ibid.

<sup>226</sup> Q89

<sup>227</sup> Q88

<sup>228</sup> Q88

<sup>229</sup> Q118

a contemporaneous running record of phone calls, emails, letters and visits and carry out a review of care every six months. The Committee heard that although the idea behind it was for all professionals involved in a person's care to provide input, in reality social workers were having to capture all the information as other professionals saw it as a social work task.<sup>230</sup>

105. Social workers are spending too much time filling in paperwork and this does not represent the best use of their skills or expertise. Despite recent efforts at reducing the bureaucratic burden on social workers this continues to be a problem and is negatively impacting on both the profession and the people who depend on it. The solution to this problem should not itself be overly bureaucratic and meaningful change could be brought about quickly and inexpensively. The Committee recommend that a task force be established with the remit and the authority to remove unnecessary and duplicated paperwork and streamline existing paperwork—though this should not be at the expense of high-quality assessments or casework. This should be completed by summer 2020. In the medium-term the Department should implement IT solutions and increase the number of administrative staff available for supporting social workers.

# 4 Mental health

## **Defining mental health**

106. The World Health Organisation defines mental health as:<sup>231</sup>

A state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.

This follows from the World Health Organisation's definition of health more broadly as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." It is possible to be in a state of poor mental health with no diagnosed mental disorder and conversely to cope well with life, be productive and enjoy a high level of mental well-being while living with a diagnosis of mental disorder.

107. A mental disorder is a diagnosed clinical condition. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, which serves as the principal authority on the diagnosis of mental disorders, defines a mental disorder as:<sup>233</sup>

A syndrome characterised by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g. political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above.

#### Mental health in Northern Ireland

108. Mental health is difficult to measure as it relies either on self-reporting, which may under-report certain conditions, or indicators such as hospitalisation rates, which only capture the more severe end of the spectrum. However, Northern Ireland appears to have a relatively high prevalence of mental health problems in the general population. It has been reported to have a 25 per cent higher rate of mental health problems than England<sup>234</sup> and significantly higher rates of depression than the rest of the United Kingdom according to prescribing trends.<sup>235</sup> Indicator 6 in the Draft Programme for Government Framework 2016–2021, which aims at improving mental health, uses as its lead measure the percentage of the population with General Health Questionnaire scores of  $\geq$ 4. The General Health Questionnaire (GHQ) is a screening tool designed to measure mental well-being in the

<sup>231</sup> World Health Organisation, Mental health: a state of well-being, accessed 28 November 2018

<sup>232</sup> World Health Organisation, Constitution of WHO: principles, accessed 28 November 2018

<sup>233</sup> Diagnostic and Statistical Manual of Mental Disorders Fifth Edition DSM-5, 2013, page 20

<sup>234</sup> Making Life Better, A whole system strategic framework for public health 2013–2023, June 2014, page 18

<sup>235</sup> Northern Ireland Audit Office, Primary Care Prescribing, 27 November 2014, page 36

<sup>236</sup> Draft Programme for Government Framework 2016–2021, 26 May 2016, pp. 55–56

general population, with a score of four or more indicating possible mental disorder. The most recent health survey of Northern Ireland found that around a fifth (18 per cent) of the population reported a score of four or more.<sup>237</sup> This number has remained fairly constant over the last decade.<sup>238</sup> Furthermore, it found that one in four (26 per cent) had concerns about their own mental health<sup>239</sup> of which three-fifths (58 per cent) sought help, with 82 per cent seeking help from their GP and 44 per cent from a family member.<sup>240</sup> Respondents in the most deprived quintile were more likely (22 per cent) to report a score of four or more than those in the least deprived quintile (15 per cent).<sup>241</sup> The age groups most likely to report a score of four or more were women aged 55–64 followed by men aged 16–24 and women aged 45–54.<sup>242</sup>

109. Northern Ireland has significantly higher rates of trauma-related disorders than other countries. A recent study by Ulster University found that Northern Ireland had the highest rate of post-traumatic stress disorder in the world—ahead of war-hit regions in the Middle East, with violence as a distinctive cause in one in four cases. Northern Ireland also has the highest suicide rate in the United Kingdom with rates steadily rising since records began in 1970. While suicides in 1970 totalled 73 this had grown to over 100 by 1978; over 200 by 2005; and rates have remained around 250–300 per year since 2008. 2015 saw the most suicides recorded (318) since records began. This number has not fallen significantly since, with 305 suicides recorded last year.

#### The Bamford Review

110. In 2002, the Department of Health, Social Services and Public Safety initiated a review, overseen by a Steering Committee chaired by Professor David Bamford of Ulster University and comprised of representatives in the mental health and learning disability fields, into the law, policies and provisions affecting people with mental health needs or a learning disability. The review envisaged a 10–15-year timescale for full implementation of its recommendations. These included:<sup>245</sup>

- continued emphasis on promotion of positive mental health;
- reform of mental health legislation;
- development of specialist services, for children and young people, older people, those with addiction problems and those in the criminal justice system; and
- an adequate trained workforce to deliver these services.

The Executive's response to the findings of the Bamford Review led to the publication in October 2009 of the 2009–2011 Action Plan. This set out a number of key actions to be

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237 Department of Health, Health Survey (NI) First Results 2017/18, 20 November 2018, page 3
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<sup>238</sup> Department of Health, Health Survey NI Trend Tables, 20 November 2018

<sup>239</sup> Department of Health, Health Survey (NI) First Results 2017/18, 20 November 2018, page 3

<sup>240</sup> Ibid.

<sup>241</sup> Department of Health, Health Survey NI Trend Tables, 20 November 2018

<sup>242</sup> Ibid.

<sup>243</sup> Ulster University, NI Has World's Highest Rate of Post Traumatic Stress Disorder, accessed 3 December 2018

<sup>244</sup> Northern Ireland Statistics and Research Agency, Suicide statistics 2017

<sup>245</sup> Department of Health, Evaluation of the 2009–2011 Bamford Action Plan, page 4

completed within associated timeframes for improving the mental health and wellbeing of the population and delivering service improvements for those with mental health needs or a learning disability through:<sup>246</sup>

- early intervention and support;
- integrated care planning with the involvement of individuals, their families and carers;
- the promotion of independence, personal fulfilment and, where possible, recovery;
- effective interagency working and partnership with community, voluntary and private sectors, appropriate to the needs of individuals;
- the recognition of the needs of families and carers throughout the lifecycle of the individual and the importance of effective transition and succession planning, information and advice;
- development of services, including specialist services, to be underpinned by standards outlined in mental health and learning disability service frameworks;
   and
- a focus on performance improvement to ensure that the patient/client experience and the quality of care delivered to individuals, families and carers is of the highest possible standard.

An evaluation of the Action Plan in 2012 identified a number of key challenges in achieving delivery. These included:<sup>247</sup>

- establishing a stepped care approach to service provision;
- enhancing the range of options available to primary care professionals to deal with the mental health needs presenting to them;
- improving access to psychological therapies;
- streamlining access to all mental health services;
- providing home based care and support as the norm for the delivery of mental health services;
- applying a systematic approach to enable the recovery of people with long term conditions;
- building up the range of specialist mental health services required to meet need;
   and
- redesigning and extending roles and retention of an effective workforce.

<sup>247</sup> Department of Health, Bamford Review Action Plan (2012–2015), November 2012, page 7

Uncompleted actions were carried through to the 2012–2015 Action Plan, which contained 76 actions. The most recent review of the 2012–2015 Action Plan was published in November 2014. It concluded that 63 actions were on target and 13 were at risk or delayed. Some of those judged to be at risk or delayed have stalled since the collapse of the Executive including implementing a revised cross-sectoral mental health strategy and progressing the next phase of the suicide prevention strategy, both of which require ministerial sign-off. A further evaluation, which would have assessed how Departments were performing against the Action Plan, was due in the spring of 2017 but not published due to the collapse of the Executive. Its preliminary findings included the need to:

- further embed and promote psychological therapies and the concept of recovery;
- provide more practical support to carers;
- improve access to services in times of mental health crisis;
- improve the experience of patients admitted to acute mental health facilities; and
- increase involvement of the voluntary and community sector.

# You in Mind pathway

111. In October 2014 the Health and Social Care Board in conjunction with the Public Health Agency published the regional care delivery pathway *You in Mind* (2014). It advocated a stepped care model which would "enhance the quality of service experience and promote consistency of service delivery across Northern Ireland." The foreword acknowledged that while "aspects of this Care Pathway are challenging to implement immediately, due to the constraints on resources, it does commit health and social care services to make better use of existing resources and to secure additional resources to address gaps in service provision."

<sup>248</sup> Department of Health, Bamford Review Action Plan (2012–2015), November 2012, pp. 31–62

<sup>249</sup> Department of Health, Bamford Review Action Plan (2012–2015), Monitoring Report, November 2014, page 3

Department of Health, Freedom of Information DOH/ 2018–0140, 22 October 2018

<sup>251</sup> Northern Ireland Assembly Research and Information Service Research Paper, Mental Health in Northern Ireland: Overview, Strategies, Policies, Care Pathways, CAMHS and Barriers to Accessing Services, Briefing Paper No. 08/17, 24 January 2017, page 16

<sup>252</sup> Health and Social Care, You in Mind, October 2014, page 4

<sup>253</sup> Ibid., page 4



Figure 6: The stepped care model

Source: Health and Social Care, You in Mind, October 2014, page 16

The stepped model of care aims to match the level of need with the level of support—the aim being to ensure that patients are referred to appropriate services and professionals with the right skills to meet their needs. Patients can be 'stepped up' or 'stepped down' depending on the need for more or less intensive specialist support and treatment with any changes arranged by the patient's existing care team.

112. The care pathway set out in *You in Mind* is built on the principle of 'recovery.' Recovery as a concept in mental health refers to an holistic model of care that aims to facilitate recovery from mental ill health by building the individual's resilience and providing support so that they may regain control over their own lives. This is envisaged as a process rather than an outcome and requires a partnership between the patient and those caring for them, with an emphasis on finding ways for the individual to live a meaningful life with or without their symptoms. The approach is consistent with the overarching strategy in healthcare of a shift towards community-based services and away from reactive models of acute care. Recovery colleges, which offer educational courses and workshops co-designed by service users, carers, and mental health professionals to assist those living with a mental health condition in their recovery are now established in all five HSC Trusts.<sup>254</sup>

113. In March 2018 the Department published the Service Framework for Mental Health and Wellbeing 2018–2021. The Framework sets out the standards and outcomes measures against which the standards and services in You in Mind will be audited. <sup>255</sup> The Framework states that: <sup>256</sup>

Many of the standards contained in the Framework do not require additional resources as they are focussed on quality improvement and should be capable of delivery by optimising the use of existing resources and funding. Where there are additional costs associated with specific standards (including

<sup>254</sup> NI Direct, Health and Social Care Trusts—Mental health, accessed 17 August 2019

<sup>255</sup> Department of Health, Service Framework for Mental Health and Wellbeing 2018–2021, March 2018, page 5

<sup>256</sup> Ibid., page 9

non-recurrent costs associated with such areas as informatics and data collection), these will be dependent upon, and sought through existing financial planning, service development and commissioning processes.

The Framework includes five standards, each with a number of service indicators, experience indicators and data sources against which to measure outcomes. These are:

- Access to mental health services: people can access mental health services when they need them;
- Assessment, formulation and diagnosis: people using mental health services
  understand the assessment process, their diagnosis and treatment options, and
  receive emotional support for any sensitive issues;
- **Personal wellbeing planning**: people using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it; people using mental health services who may be at risk of crisis are offered a crisis plan;
- **Care and treatment**: people using mental health services, and their families or carers, feel optimistic that care will be effective;
- **Staying engaged and self-management**: people using mental health services are actively involved in shared decision-making and supported in self-management.

114. The framework will be completed in two phases. Phase 1 will use existing sources of performance and experience data to report on progress against each standard, while Phase 2 will commence in 2019–20 and utilise newly developed methods of data collection that it is hoped will provide more standardised, practice-based evidence for monitoring performance.<sup>257</sup>

# Funding for mental health

115. Mental health is sometimes referred to as a 'Cinderella service' that has been historically undervalued and underfunded. However, there is now a broad consensus around the value of effective mental healthcare and the principle of 'parity of esteem' between mental and physical health. Parity of esteem has been defined as "equal access to effective care and treatment; equal efforts to improve the quality of care; equal status within health care education and practice; equally high aspirations for service users; and equal status in the measurement of health outcomes." A commitment was made by the last Health Minister to achieving parity of esteem between mental and physical health, meaning that "mental health would, in time, receive the allocation of attention, effort and resources on a basis which fully meets local needs." <sup>259</sup>

116. Despite many of the positive changes made in the wake of the Bamford Review funding for mental health as a proportion of the health budget in Northern Ireland has remained comparatively low, despite the higher prevalence of need. In 2015–16, spending on mental health totalled £255 million, which represents 5.5 per cent of the overall health

<sup>257</sup> Department of Health, Service Framework for Mental Health and Wellbeing 2018–2021, March 2018, pp. 24–25

<sup>258</sup> Royal College of Psychiatrists, Whole-person Care: from rhetoric to reality, 2013

<sup>259</sup> Department of Health, O'Neill launches new mental health recovery services, 13 October 2016

budget.<sup>260</sup> In 2016–17, 5.2 per cent of the health budget was spent on the Mental Health Programme of Care by HSC Trusts (not including spend on mental health services delivered by GPs or the Public Health Agency, which the Department does not collect data on).<sup>261</sup> By comparison, 13 per cent of total expenditure by clinical commissioning groups and specialised commissioning services (not including direct commissioning such as that by general practitioners) was spent on mental health by NHS England in 2015–16, with 13.3 per cent spent in 2016–17 and 2017–18.<sup>262</sup> NHS Wales allocated 11.4 per cent of expenditure to mental health in 2017–18<sup>263</sup> and NHS Scotland allocated 7.6 per cent in 2019–20.<sup>264</sup>

117. Start360, a charity based in Northern Ireland working with marginalised young people and vulnerable adults, told us that funding allocated to mental health is "nowhere close to the amount needed to provide adequate support for all those who need it" while the Royal College of Psychiatrists told us that mental health funding should be closer to 13 per cent of the overall health budget. Many contributors emphasised the contrast between Northern Ireland's lower proportional spend on mental health when set against its higher need. Health when set against its higher need. The same proportional spend on mental health when set against its higher need.

118. We heard of a number of impacts that underfunding is having on mental healthcare in Northern Ireland. Action Mental Health told us that its New Life Counselling service, which provided 2,000 free counselling sessions last year, was not sustainable due to a lack of funding.<sup>268</sup> The British Psychological Society Northern Ireland highlighted the underfunding of clinical psychology training numbers and posts, 269 claiming that out of over 250 applications only 11 training places could be allocated and that this had recently been scaled down to seven. <sup>270</sup> The British Association for Counselling and Psychotherapy pointed to PPR's findings that, following cuts to expenditure for counselling provision to GPs, "less than two thirds of all GP practices in Northern Ireland are currently able to offer access to in-house counselling."271 Inspire emphasised the impact that budget cuts had had on the community and voluntary sectors, telling us that "if there is a cut to funding or a challenge on funding, one of the easy hits is to reduce funding to our sector."272 The Royal College of Psychiatrists brought attention to the fact that increases in expenditure for mental health initiatives and services announced by the Secretary of State for Health and Social Care do not necessarily translate across to Northern Ireland in Barnett consequentials as "while the money may come to Northern Ireland, it does not mean that expenditure will be on the same services."273 The College identified the "lack of

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260
     Minister of Health, Answer to written question AQW 3186/16-21, 4 November 2016
     Department of Health, Freedom of Information DOH/2018-0010, 9 February 2018
     Secretary of State for Health and Social Care, Answer to written question 195072, 3 December 2018
     Welsh Government, NHS Expenditure Programme Budgets, 2017-18, 10 April 2019, page 1
     Based on figures from the Scottish Budget 2019–2020, accessed 19 August 2019
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     Start360 (HTH0019)
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     Action Mental Health (HTH0013); British Association for Counselling and Psychotherapy (HTH0006); British
      Association of Social Workers Northern Ireland (HTH0022); Q267
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     British Association for Counselling and Psychotherapy (HTH0006)
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parity of esteem for mental health services" and "a relative underfunding of mental health services compared to acute services" as among the main issues facing mental healthcare in Northern Ireland.

119. Despite a higher prevalence of need, the Department of Health spends a comparatively low percentage of its overall budget on mental health. Years of underfunding have meant that those in need of mental health services have struggled to access the same quality of care as those with physical health needs. The Department should increase its level of investment in mental health as a share of the overall health budget in line with recent increases in other UK jurisdictions, with the aim of reaching 13 per cent in the long-term.

120. The Confidence and Supply Agreement pledged a total of £50 million specifically for mental health, at £10 million per annum for five years. For 2018–19, Parliament approved a further £410 million to be added to the grant to the Northern Ireland Executive, with £30 million allocated specifically to address mental health and severe deprivation. $^{274}$ 

121. The Royal College of Psychiatrists stated in correspondence with the Committee that "there has been a long-standing underfunding of mental health services in Northern Ireland and [ ... ] this shortfall will not be addressed by the additional [Confidence and Supply] funding."<sup>275</sup> Furthermore, the College told us that "short-term and time-limited projects will not, in our opinion, be of benefit for mental health services."<sup>276</sup> They provided a list of potential projects with estimated costings that the College believed would deliver long-term savings to the Department, including:<sup>277</sup>

- physical healthcare monitoring for those with severe mental illness and eating disorders to reduce premature deaths and associated costs from diabetes and cardiovascular disorders;
- early intervention in psychosis services to reduce acute psychiatric admissions as well as the morbidity associated with psychosis;
- investment and planning in services for patients with Alcohol Related Brain Damage (ARBD) to prevent inappropriate placement in dementia care homes and hospital bed stays;
- establishing multi-disciplinary integrated mental health liaison teams to service
  acute hospitals, providing a comprehensive 24-hour self-harm service which
  would contribute to suicide prevention together with a comprehensive substance
  misuse liaison service which would contribute to a reduction in the morbidity
  associated with substance misuse;
- dedicated dementia home support teams to provide a framework for understanding the causes of challenging behaviours within the context of a person's specific needs, enabling the appropriate management of patients and reducing costs associated with challenging behaviour, particularly within community residential facilities;

<sup>274</sup> Northern Ireland Office, Supplementary Estimates Memorandum 2018–19, 1 May 2018, page 15

<sup>275</sup> Correspondence from the Royal College of Psychiatrists relating to underfunding of mental health services in Northern Ireland, 29 November 2018

<sup>276</sup> Ibid.

<sup>277</sup> Ibid.

- a dedicated perinatal service for Northern Ireland to prevent women who
  develop perinatal mental health difficulties from going on to develop more
  marked symptoms and requiring more specialist support;
- enhanced community services for patients with a learning disability to reduce acute bed stays for patients with challenging behaviours;
- enhancement of addictions teams throughout Northern Ireland.

122. However, in a response to a Freedom of Information request issued on 29 June 2018, the Department stated that the £10 million of Confidence and Supply funding allocated to mental health that year would be spent on addressing increasing pressures on services, including increases in costs due to inflation and "addressing funding gaps to ensure that current services are not stopped."<sup>278</sup>

123. The Committee heard concern that Confidence and Supply funding was being used to relieve existing pressures rather than on developing new care pathways or other much needed transformation projects. Professor Nichola Rooney, Chair of the British Psychological Society Northern Ireland commented:<sup>279</sup>

The non-recurrent nature makes it very difficult to use this money in a way that is transformative. Even in terms of training, there are very few programmes that train people in less than a year that would make substantial changes. A lot of money has gone towards cost pressures for previous ministerial agreements, but there is very little opportunity for innovation and change.

124. We heard that consultation between the Department and the wider sector on where to allocate funding appears to have been lacking. David Babington, Chief Executive of Action Mental Health told us that the first he had heard of the funding was "in the public domain, on BBC News." When asked whether there was a particularly close working relationship between the community and voluntary sectors and the Department of Health, Professor Peter McBride, Chief Executive of Inspire told us that "it is fair to say there is not a joined-up approach." Action Mental Health further commented: <sup>281</sup>

Exactly where this funding has gone is unclear, it appears it has gone to relieve increasing pressures, with £6 million going to [...] projects including Talking Therapy hubs, drug and alcohol abuse and forensic mental health. Effectively the new money is not having any new impact.

125. In the absence of a mental health strategy measures should be taken to ensure that Confidence and Supply funding ring-fenced for mental health is being used as effectively as possible. The Committee recommends that the Department consult widely with professionals, service users, staff, and the community and voluntary sectors on where funds would be most effectively deployed and to make this information clearly available to the public so that decisions can be properly scrutinised. Furthermore, the Department's decision to use funding to maintain existing services raises the prospect

<sup>278</sup> Department of Health, Freedom of Information, DOH/2018-0070, 29 June 2018

<sup>279</sup> Q272

<sup>280</sup> Q27

<sup>281</sup> Action Mental Health (HTH0013)

of what will happen once the deal expires. The Department should set out how it will respond to the exhaustion of additional funds for those programmes supported by the Agreement in 2018–19 and 2019–20.

## Mental health strategy

126. The Committee heard that mental health in Northern Ireland was operating within a policy vacuum and this was preventing long-term, strategic investment in service improvements. The Committee heard that this was needed in a number of areas and that much of the ambition of Bamford had yet to be realised. In particular, we heard concerns raised over:

- prevention and early intervention;
- availability of psychological therapies;
- access to services in times of mental health crisis;
- the experience of patients admitted to acute mental health facilities; and
- involvement of the voluntary and community sector.

127. This was made most clear to us in our session with service users. Rev. Dr. Scott Peddie, who has lived with a diagnosis of bipolar affective disorder for 10 years and a diagnosis of major depressive disorder before that, has experience of accessing services in both Scotland and Northern Ireland and compared his experiences in Northern Ireland unfavourably:<sup>282</sup>

I was a service user in Scotland about 16 years ago and I remember there, when I went along for my appointments, we would go into a shiny new hospital where you would see the psychiatrist very quickly, you would be referred to other psychological therapists. That worked really well, in hindsight. Here it is very different. You will go along to a dilapidated building, primarily with paint falling off the walls sometimes, and it promotes this stigma almost of mental health being different to physical health.

Rev. Dr Scott Peddie further commented that the "parity of esteem issue is very closely felt in mental health because you do feel as if you are right at the bottom of the pile in terms of health provision."<sup>283</sup>

128. Inspire told us that "effective recovery may involve a combination of medical, psychological and community-based services" and that "for some people a range of these services is needed all the time, while others may best be served by one service or by progressing from one to the other." However, the service users we heard from had experienced difficulties in accessing and transitioning through a full range of therapies, particularly psychological therapies. Rev. Dr Scott Peddie told us:<sup>284</sup>

Here in Northern Ireland [ ... ] it is very much focused on medication, which in my case with bipolar disorder, medication is really important that

<sup>282</sup> Q133

<sup>283</sup> Q147

<sup>284</sup> Ibid.

you get that right. But in order to help people to live a meaningful and productive life, you need to have psychological therapy as well, or certainly I did, and it just was not there.

Rev. Dr Scott Peddie told us that HSC staff were working "with their hands tied behind their back, in that they cannot offer you the services that would be best for your condition" 285 and that he had to go private to get the treatment he required. 286 Catherine O'Reilly told us that "the first thing you get offered is medication, when really the most beneficial things I found were learning coping skills." She contrasted a recovery-based programme provided by the voluntary sector through which she was engaged in meaningful work with the support of an understanding community with the services provided by the HSC which "don't leave you with a lot of hope." 288

129. Particular concern was also raised over a lack of continuity in care. Catherine O'Reilly said that "with some of the initiatives, you are given a course and it lasts maybe six weeks, and then after that there is nothing. It does not go anywhere." Speaking of his experience as an inpatient, Rev. Dr Scott Peddie told us:<sup>290</sup>

I felt very much as if it was a warehousing exercise, if you like. You go into the ward and you are given your drug treatment. You may, if you are lucky, get some input from a psychologist but that is quite difficult to get. Then you find when you are discharged you have to go on a waiting list to see another psychologist, so there is not that continuity of care there, which is detrimental, at least from my perspective. That is how I experienced it.

This was more common in certain Trust areas than in others, with service levels being described as "very patchy" across locations.<sup>291</sup>

130. Inspire told us that "a suite of appropriate stepped services that are available when people require them" is necessary for the treatment of a wide variety of experiences but that "current systems are not joined up and suffer from limited or no cross sectoral careplan management and frequently, have no information sharing protocols." They went on to say: <sup>293</sup>

Although significant pieces of work have been undertaken to develop effective care planning, to date none of the suggestions put forward have been implemented and remain 'on the shelf.' Clear direction and leadership is required to ensure the solutions identified are introduced as a matter of urgency.

This point was also made to us by the Compass Advocacy Network, who told us that "the evidence of Joint-Up working by departments (which is critical to the implementation of

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     Inspire (HTH0045)
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293
     Ibid.
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Bamford) is scant—there continues to be a lot of 'lip service' and a lack of follow through" and that "we see this situation becoming heightened whilst we continue to exist in a political vacuum." <sup>294</sup>

131. The experiences we heard with respect to the availability of care in times of mental health crisis were particularly negative. Catherine O'Reilly told us "if you are in a situation where you do not feel safe, you are told that you can avail of ringing up the out-of-hours doctor, but [ ... ] it takes six hours for an out-of-hours doctor to contact you" going on to say "if I had to say something to somebody who is in that situation, I would tell them to ring the Samaritans or Lifeline. That is the best thing to do." Rev. Dr Scott Peddie told us: 296

You may present as being suicidal and you will go perhaps to a crisis response team, and they will make a decision as to whether you are admitted to hospital, which these days is increasingly unlikely. If you are admitted to hospital it is really a lottery. You could be sent anywhere in Northern Ireland. A lot of the time you are sitting waiting for a bed to come up, so that is a big issue and that impacts on people in terms of the trauma that they suffer as well. The resources are not there when people go forward. [ ... ] When you go through a crisis it is incredibly tough and you really need to have the resources there in order to help you through that. Those resources, as far as I can see and as far as I have experienced, are not there to make that impact. I have no doubt that that impacts on suicide figures.

- 132. Inspire told us that presenting at Accident and Emergency was often the only route available to access assistance in times of crisis and that alternative models of emergency mental healthcare were required, claiming that "rather than the current piecemeal approach to mental healthcare provision, the implementation of an effective, wrap-around mental health services strategy is urgently required."<sup>297</sup>
- 133. The general consensus was that the ambition of Bamford had yet to be realised and a refreshed strategy was needed urgently to direct investment into service transformation. In our session with mental health organisations, when asked what the priority of the next Health Minister should be, every one of our witnesses said that their number one priority would be a fully resourced mental health strategy.<sup>298</sup> Dr Gerry Lynch, Chair of the Royal College of Psychiatrists in Northern Ireland told us:<sup>299</sup>

The time has come to build on Bamford and its many achievements. There are some things that Bamford has not achieved [ ... ]. We would like to see the publication of the evaluation report and develop [ ... ] a strategy similar to the one they have in Scotland or, in England, the five-year forward view, which builds on Bamford but refreshes it and looks forward, because [ ... ] the strategy for Bamford began as far back as 2002.

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294 Compass Advocacy Network (HTH0003)
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<sup>295</sup> Q128

<sup>296</sup> Q144

<sup>297</sup> Inspire (HTH0045)

<sup>298</sup> Q310

<sup>299</sup> Q269

Dr Lynch went on to say that in the absence of a strategy there was a lack of clear leadership and meetings with the Department to decide on priorities had been taken "on an ad hoc basis." This had been brought to the fore with the announcement of extra funding for mental health through the Confidence and Supply Agreement. Professor Peter McBride told us that "in the absence of a mental health strategy, it is very hard to create a narrative around why that money should not be spent on what is easily presented as a critical situation in the acute sector" and that "very little came into prevention, mental health promotion or community-based support." 100 mental health promotion or community-based support." 101 mental health promotion or community-based support.

134. In the absence of a strategy, a number of community and voluntary organisations described being treated as "low-hanging fruit" in budget decisions, with core services protected at their expense.<sup>302</sup> Professor McBride commented:

I cannot stress this enough. There is a huge need for us to create a strategy, on which we all agree, that we can work towards. That would allow each of us to fulfil our responsibilities, recognising that we will all have to make concessions, perhaps start collaborating, and work genuinely in partnership together to achieve the vision of that strategy. In the absence of that, we all end up fighting for our own corner and sometimes fighting with each other.

135. Mental health services in Northern Ireland are not delivering the model of care that Bamford envisaged. In the absence of clear lines of decision-making in mental health, Northern Ireland is in need of a comprehensive, up-to-date mental health strategy that will provide the direction necessary for developing collaborative partnerships and services that are capable of meeting the dynamic needs of service users. The Committee recommends that the Department publish the latest Bamford evaluation and use this as a first step to begin work on the mental health strategy for Northern Ireland in collaboration with the HSC Trusts, professionals, service users, staff, and the community and voluntary sectors.

#### **Child and Adolescent Mental Health Services**

136. The regionally agreed service model for the organisation and delivery of Child and Adolescent Mental Health Services (CAMHS) was published in 2012 and aimed to provide "a framework against which to remodel CAMH service provision, thus promoting an improved and more consistent approach across all Trust areas." It agreed a needs-based care pathway based on the stepped care model, whereby interventions are 'stepped up' or 'stepped down' as clinically required. The service model was developed in response to the Bamford report *A Vision of a Comprehensive Child and Adolescent Mental Health Service* (2006). 305

137. While figures were not provided on the level of funding required to implement fully the model across the region it was acknowledged that aspects of the model would

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300 Q284
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<sup>301</sup> Q272

Association for Real Change Northern Ireland (<a href="https://https:/

<sup>303</sup> Department of Health, Child and Adolescent Mental Health Services: a Service Model, 31 July 2012, page 3

<sup>304</sup> Ibid., page 6

<sup>305</sup> Department of Health, A Vision of a Comprehensive Child and Adolescent Mental Health Service, July 2006

require additional funding.<sup>306</sup> However, the Committee heard that CAMHS had in fact been subject to chronic underfunding. In 2017 only 7.8 per cent of Northern Ireland's mental health budget was allocated to CAMHS.<sup>307</sup> The Health and Social Care Board have calculated that investment in CAMHS should be around 10 per cent of the mental health budget, an acknowledged funding gap of £4.8 million.<sup>308</sup> According to the most recent full year budgeting information reviewed by the Northern Ireland Commissioner for Children and Young People, approximately £30 million was spent on CAMHS in 2015–16, which equates to 0.8 per cent of the health budget and less than 1p in every pound invested.<sup>309</sup> Of this funding, the majority was invested in steps 3–5, which are statutory services<sup>310</sup> and less than 8 per cent of spend on statutory services went to under-18s.<sup>311</sup> This is despite research showing that half of all mental disorders begin by the age of 14.<sup>312</sup>

138. Hearing evidence from service users, when asked about her experience of mental health services as a young person, Catherine O'Reilly described a "sticking plaster" approach which was "okay enough to keep me alive and functioning" but that the tools she needed were ultimately provided by the voluntary sector—whereas in the statutory sector she had been diagnosed and prescribed antidepressants by a psychiatrist. In her case, this had not helped. This reflected a widely held concern that mental health services in Northern Ireland, both child and adult, were still overly reliant on medication. Lynda Wilson, Director of Barnardo's Northern Ireland told us: 16

We need to look at the total system and have a system that allows young people to step up and step down, to get intensive interventions when they need them quickly and to be seen quickly, so we know what pathway they need to be directed to, so they have somebody who is there with them early on.

139. The Committee heard that implementation of the service model had not been carried out in a unified or consistent manner and that, in common with adult mental health services, provisions were more developed in some HSC Trust areas than in others.<sup>317</sup> We also heard that services were fragmented, with a lack of parity of esteem between prevention and early intervention services (steps 1–2) and more specialist mental health services (steps 3–5).<sup>318</sup> We were told that early intervention could help prevent mental health conditions from progressing into adult life and that this would reduce the need for more costly acute services.<sup>319</sup> Yet the majority of services in steps 1 and 2 are provided by the community and voluntary sectors, which have reported reductions in funding and a

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Department of Health, Child and Adolescent Mental Health Services: a Service Model, 31 July 2012, page 5
      Northern Ireland Commissioner for Children and Young People, 'Still Waiting', September 2018, page 3
     Northern Ireland Commissioner for Children and Young People (HTH0049)
309
      Northern Ireland Commissioner for Children and Young People, 'Still Waiting', September 2018, page 227
310
      Northern Ireland Commissioner for Children and Young People (HTH0049)
      Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE, Lifetime prevalence and age-of-onset
      distributions of DSM-IV disorders in the National Comorbidity Survey Replication, July 2005
313
      Q126
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      Q128
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     British Association for Counselling and Psychotherapy (HTH0006)
317
     Northern Ireland Commissioner for Children and Young People (HTH0049)
318
     Ibid.
319
      Q270
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lack of formal support from Government.<sup>320</sup> We were told that "service commissioners need to more routinely consider the wider opportunities that can come from distributing this funding to the [community and voluntary sectors]."<sup>321</sup>

140. This reflected a fragmentation of commissioning more broadly. The Northern Ireland Commissioner for Children and Young People told us that it was difficult to identify appropriate funding sources for innovations or changes to services and that "in some cases staff must approach a number of commissioners across different Directorates to fund important work." The Commissioner argued that serious consideration should be given to a reconfiguration of the Health Programmes of Care rather than "continuing with structures and processes that are aligned to outdated historical legacies." 323

141. The Committee heard that the Education Authority was not aligning itself with the stepped care model, perceiving it to be relevant only to statutory mental health services and not the education system. <sup>324</sup> This was also apparent in other parts of the system, such as Accident and Emergency, suggesting a lack of collaborative working and understanding of professionals' roles in supporting children and young people's mental health and wellbeing. <sup>325</sup> Lynda Wilson called for earlier intervention in primary schools as "we cannot afford the intensive interventions that are required when young people get to the other end of the line." <sup>326</sup> Professor Nichola Rooney, Chair of the British Psychological Society Northern Ireland, told us that there needed to be "better joined-up working between health and education, and CAMHS services and education services." <sup>327</sup> She described a system characterised by a lack of understanding, collaboration and access: <sup>328</sup>

There are some projects going ahead, and pockets of very good practice, but there are wide areas within schools where the teachers are not trained to deal with the presentations. They feel that the children fall between stools. If they take them to A&E or CAMHS, they are told they are not severe enough and they do not have a mental illness. If they go to primary healthcare hubs, they are told they are too risky because they are self-harming. They have limited access to educational psychology, because there are, in one school, 1,600 people, five hours of educational psychology and only 15 children allowed to be statemented. They are choosing, in very difficult circumstances, who should have access to these services.

142. The dominant themes of the evidence we heard on Children and Adolescent Mental Health Services were of underfunding and fragmentation. The acknowledged funding gap must be closed by the Health and Social Care Board. We recommend that spending on CAMHS is brought into line with the HSCB's own recommendation of 10 per cent of the mental health budget. To ensure that funding is deployed strategically measures should be taken to better integrate the commissioning of services and develop a culture of multi-disciplinary and multi-sectoral team working. The recent review into CAMHS

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320 Inspire (<u>HTH0045</u>); Northern Ireland Commissioner for Children and Young People (<u>HTH0049</u>); Start360 (HTH0019); Q295
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<sup>321</sup> Northern Ireland Commissioner for Children and Young People (HTH0049)

<sup>322</sup> Ibid.

<sup>323</sup> Ibid

<sup>323</sup> Ibid

<sup>324</sup> Ibid.325 Ibid.

<sup>325</sup> IDIO

<sup>326 &</sup>lt;u>Q99</u>

<sup>327</sup> **Q295** 

<sup>328</sup> Q294

conducted by the Northern Ireland Commissioner for Children and Young People contained a number of recommendations based on wide-ranging consultations with key stakeholders. We agree with the Commissioner's recommendation that a long term and sustainable 'funding and practice partnership' model be established for driving change which takes account of the investment required across all key services and sectors included in the stepped care model.

#### Suicide

143. Northern Ireland has been described as facing a "suicide epidemic." Incidences of suicide have been steadily rising since records began in 1970 along with a widening of the gap in rates between men and women. More people have died from suicide since the signing of the Belfast Agreement than died in over thirty years of the Troubles. 331

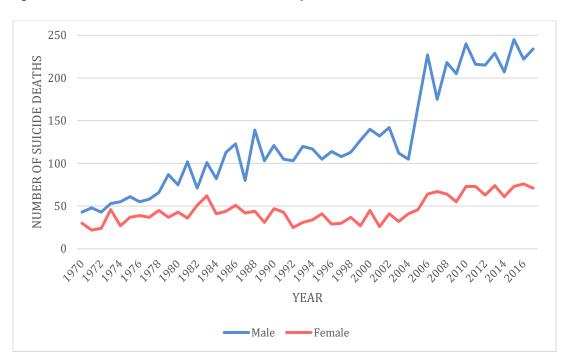


Figure 5: Suicide deaths in Northern Ireland, 1970-present

Source: Northern Ireland Statistics and Research Agency, Suicide deaths 2017, 7 November 2018

144. The reasons behind these trends are not well understood. The Committee was told that suicide is "a very complex phenomenon" and that more research was needed before attributing causality. However, recent research has pointed to the legacy of the Troubles as likely playing a key role in these trends. 334

<sup>329</sup> The Independent, Northern Ireland is facing a suicide epidemic—but continues to be ignored in UK mental health funding, 4 June 2018

<sup>330</sup> Office for National Statistics, Suicides in the UK: 2017 registrations, 4 September 2018

Based on 4,630 suicides registered between 1999–2017 and 3,532 deaths attributed to the Troubles between 1969–2001.

<sup>332</sup> Q273

<sup>333</sup> Q302

Commission for Victims and Survivors, Towards A Better Future: The Trans-generational Impact of the Troubles on Mental Health, March 2015

145. Uniquely in the United Kingdom however, and despite its higher need, Northern Ireland does not have an up-to-date suicide prevention strategy in place. Its most recently implemented strategy, *Protect Life*, covered from 2006 until March 2011 with an updated version covering until March 2014. A consultation on a new suicide prevention strategy for Northern Ireland, *Protect Life 2*, was launched by the Department of Health in September 2016. The draft strategy set out a number of wide-ranging objectives including: reducing incidences of repeat self-harm; restricting access to the means of suicide; strengthening the evidence base on suicide patterns; identifying and responding to emerging suicide 'clusters;' the provision of information and support for those affected by suicide; and enhancing responsible media reporting. However, it has remained in draft since the collapse of the Executive.

146. While there was some scepticism over the efficacy of prevention strategies, given that suicide rates continued to rise under the original *Protect Life*, there was broad agreement that effective suicide prevention required the cross-departmental, coordinated and evidence-based approach contained in *Protect Life 2.*<sup>337</sup> Speaking to the Committee, the Permanent Secretary at the Department of Health told us that under the Northern Ireland (Executive Formation and Exercise of Functions) Act 2018 the Department would now be able to bring forward the strategy. However, the Permanent Secretary remarked that it has "potentially significant resource implications" and the decision would be deferred "until we see the 2019–20 financial settlement."<sup>338</sup>

147. Urgent action must be taken to bring down suicide rates in Northern Ireland. The comprehensive measures set out in Protect Life 2 are evidence-based and would provide clear direction and focus for tackling Northern Ireland's suicide epidemic. The Committee recommends that the Department implement the Protect Life 2 strategy as soon as the next budget is agreed.

<sup>335</sup> Department of Health, The Northern Ireland Suicide Prevention Strategy 2012–March 2014

<sup>336</sup> Department of Health, Protect Life 2: a draft strategy for suicide prevention in the north of Ireland, pp. 8-11

<sup>337</sup> Q273

<sup>338</sup> Q332

# 5 Oral health

#### Oral health in Northern Ireland

148. Northern Ireland has some of the worst children's dental health outcomes in the United Kingdom. According to the most recent Children's Dental Health Survey:

- 44 per cent of 5-year-olds were deemed to have good oral health (defined as the absence of obvious decay experience, no tooth surface loss into dentine and the absence of calculus). This fell to 31 per cent of 8-year-olds and 19 per cent of 15-year-olds;<sup>339</sup>
- 42 per cent of 5-year-olds and 57 per cent of 8-year-olds showed signs of clinical decay in primary teeth. With respect to permanent teeth, almost a quarter (24 per cent) of 8-year-olds, 60 per cent of 12-year-olds and 75 per cent of 15-yearolds showed signs of clinical decay;<sup>340</sup>
- 19 per cent of children aged 5 showed signs of severe or extensive tooth decay. By the age of 15 this had increased to 36 per cent. By comparison, 13 per cent of 5-year-olds in England showed signs of severe or extensive tooth decay and this rose to 14 per cent at age 15. In Wales the figure was 22 per cent for both age groups.<sup>341</sup>

149. The survey went on to reveal the impact that poor oral health was having on children's lives. Some of these included:<sup>342</sup>

- 34 per cent of 12-year-olds and 27 per cent of 15-year-olds felt embarrassed smiling or laughing;
- 21 per cent of 12-year-olds and 17 per cent of 15-year-olds had difficulty eating;
- 10 per cent of 12-year-olds and 6 per cent of 15-year-olds had difficulty speaking;
- 4 per cent of 12-year-olds and 3 per cent of 15-year-olds had difficulty doing schoolwork because of their oral health.

150. Tooth decay is the number one reason for child hospital admissions in Northern Ireland.<sup>343</sup> An analysis by the British Dental Association estimated that, based on 5,122 children aged 18 or under admitted to hospital for the removal of 22,699 teeth in 2016–17, the cost to the health service would have been approximately £9.3 million.<sup>344</sup>

151. The cost of poor oral health carries into adulthood, with gum disease linked to a number of health problems in later life, including heart disease and heart attacks,

<sup>339</sup> NHS Digital, Children's Dental Health Survey, Country specific report: Northern Ireland, 19 March 2015, page 12

<sup>340</sup> Ibid., page 16

<sup>341</sup> NHS Digital, Children's Dental Health Survey, Executive Summary England, Wales and Northern Ireland, 19
March 2015, page 5

<sup>342</sup> NHS Digital, Children's Dental Health Survey, Country specific report: Northern Ireland, 19 March 2015, page 35

<sup>343</sup> Department of Health, Acute episode based activity 2017/18, Volume 4: Healthcare Resource Group (HRG), 17 October 2018, page 16

<sup>344</sup> British Dental Association, Multi-million pound price of inaction on kids teeth in Northern Ireland, 12 March 2018

diabetes, stroke and rheumatoid arthritis.<sup>345</sup> Poor oral health may also have an impact on employment prospects—a recent YouGov poll found that 77 per cent of respondents believed that visibly decayed teeth or bad breath would hinder someone's chances of securing a public or client facing role.<sup>346</sup> This compared with 43 per cent who felt the same way about not adhering to dress codes and 38 per cent about being overweight.<sup>347</sup>

152. While the proportion of adults who are edentate (have no teeth) has fallen significantly in recent decades,<sup>348</sup> the ongoing maintenance of heavily restored teeth poses a different challenge for older people. Brushing twice a day may become more difficult for those with a long-term health condition, reduced dexterity or dementia and many regularly prescribed medications have the side-effect of causing dry mouth, which increases the risk of tooth decay and oral infections.<sup>349</sup> Along with pain and the broader impact on a person's quality of life, poor oral health has been linked with malnutrition and an increased risk of pneumonia in older people.<sup>350</sup>

## **Oral health strategy**

153. Northern Ireland's oral health strategy dates back to 2007 and has never been formally reviewed. The targets set out in the strategy extend only to 2013 and are based on data obtained in the 2003 dental health survey. We were told that very little information had been shared by the Department on where funds allocated to dental services were being allocated and prioritised and that in the absence of a coordinated plan or any fresh targets to work towards opportunities were being missed and progress was stagnating. 352

154. The Committee heard that dentists had an important role to play in health promotion and upstream intervention in areas such as diabetes, obesity and certain cancers.<sup>353</sup> Research has also pointed to the effectiveness of dental teams in promoting tobacco cessation<sup>354</sup> and even in recognising signs of abuse and neglect—contributing to a multiagency approach to safeguarding.<sup>355</sup> The British Dental Association told the Committee that an acknowledgement of these wider benefits was "badly needed" by the Department and that "much more can be achieved simply by better co-ordination of resources and stakeholders, and a fresh ambitious vision for the improvements we want to make."<sup>356</sup>

155. We were provided with examples of initiatives that had the potential to deliver long-term savings for the Department, including a universal nursery tooth brushing programme which the British Dental Association estimates could save the Department £1 million over five years based on results secured using similar models in Scotland and Wales; investment in prevention to bring down the cost of hospital admissions for child

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345 NHS, The health risks of gum disease, accessed 21 August 2019
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<sup>346</sup> YouGov Plc's poll for the British Dental Association, accessed 21 August 2019

<sup>347</sup> Ibid.

<sup>348</sup> NHS Digital, Adult Dental Health Survey 2009—Northern Ireland Key Findings, 24 March 2011, page 5

The Faculty of Dental Surgery of The Royal College of Surgeons of England, Improving older people's oral health, August 2017, page 4

<sup>350</sup> Ibid., pp. 4-5

<sup>351</sup> Department of Health, The Oral Health Strategy for Northern Ireland—June 2007, accessed 28 August 2019

<sup>352</sup> British Dental Association Northern Ireland (HTH0021)

<sup>353</sup> Correspondence from the British Dental Association Northern Ireland relating to the absence of an Oral Health Strategy, 22 November 2018

<sup>354</sup> Alan B Carr and John Ebbert, Interventions for tobacco cessation in the dental setting, 13 June 2012

<sup>355</sup> Public Health England, Safeguarding in general dental practice, 3 April 2019

Correspondence from the British Dental Association Northern Ireland relating to the absence of an Oral Health
Strategy, 22 November 2018

teeth extractions under general anaesthetic; and extending the HPV vaccine to boys as a cost-effective way to bring down rates of oral disease and cancer.<sup>357</sup> The British Dental Association suggested that some child public health initiatives could be funded using additional monies raised from the Soft Drinks Industry Levy,<sup>358</sup> as has been the case in England.<sup>359</sup> However, the Department has stated that additional monies raised from the levy have gone into the overall budget,<sup>360</sup> raising concern that funds have been used to shore up holes in existing services rather than on preventative or transformative projects.<sup>361</sup>

156. When asked by the Committee what progress was being made towards developing an up-to-date oral health strategy for Northern Ireland, the Permanent Secretary told us that "a lot of what is in [the 2007] strategy remains fit for purpose, but there are some issues we need to look at." We were told that a meeting had been scheduled with the chair of the British Dental Association to discuss the issue further. However, to date, no commitment has been announced by the Department to develop a new oral health strategy for Northern Ireland.

157. Northern Ireland has some of the poorest oral health outcomes in the United Kingdom. The current oral health strategy is based on obsolete data from 2003 and does not contain any up-to-date targets for optimising services and improving outcomes. Fresh direction and impetus are needed to improve Northern Ireland's oral health. This will not be achieved with a piecemeal approach but requires an overarching, evidence-based strategy with associated targets to work towards. The Committee recommend that the Department commit to developing a new oral health strategy for Northern Ireland in collaboration with the dental profession to be published in draft by early 2021.

<sup>357</sup> British Dental Association Northern Ireland (HTH0021)

<sup>358</sup> Ibid

<sup>359</sup> HM Treasury, Soft Drinks Industry Levy comes into effect, 5 April 2018

<sup>360</sup> Department of Health, Freedom of Information, DOH/2018-0061, 14 June 2018

<sup>361</sup> British Dental Association, Investing in oral health: Northern Ireland's lost sugar tax windfall, 19 December 2018

<sup>362</sup> Q325

<sup>363</sup> Ibid.

# **6** Community pharmacy

## **Community pharmacy in Northern Ireland**

158. Community pharmacists are independent contractors responsible for the processing and dispensing of prescription and over the counter medicines. In addition to their dispensing function community pharmacists also provide a range of patient-centred services and take part in public health promotion campaigns.

159. A recent survey found that an estimated 15 million informal interventions take place in community pharmacies across Northern Ireland each year, of which 4.4 million (almost 30 per cent) were likely to have prevented harm to patients. An estimated 850,000 cases of potential patient harm are prevented annually through medicines optimisation interventions by community pharmacists. Over 2.5 million interventions for minor ailments or over the counter advice and support are provided in community pharmacies each year, with 700,000 provided to children. Over 360,000 referrals to health and social care professionals are made by community pharmacists annually. The majority of these are to General Practice, though an estimated 80,000 are made to out-of-hours centres and emergency departments, with a further 30,000 signposted to community and voluntary support centres.

160. Community pharmacists also make a wide range of public health-related interventions each year. These include:<sup>369</sup>

- antibiotics use advice;
- medicines waste advice;
- advice on safe storage of medicines;
- addiction support;
- mental health support;
- immunisation provision or advice;
- health checks;
- sexual health advice;
- advice on stopping smoking;
- exercise advice;
- weight management advice;
- dietary advice;

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364 Community Pharmacy NI, Community Pharmacy.... the best kept secret, November 2016, page 4
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<sup>365</sup> Ibid., pp. 5–6

<sup>366</sup> Ibid., page 7

<sup>367</sup> Ibid., page 8

<sup>368</sup> Ibid.

<sup>369</sup> Ibid., page 9

- alcohol consumption advice;
- sun care advice;
- travel advice;
- advice on malaria prophylaxis;
- community and social care support.

161. In addition to these informal interventions, community pharmacies in Northern Ireland run a range of services formally commissioned by the HSC. Each year, the average Northern Ireland pharmacy:<sup>370</sup>

- looks after the routine medicine supply for around 3,000 regular patients;
- dispenses around 72,000 prescriptions;
- provides around 120 Medicines Use Reviews for patients with asthma & diabetes;
- supports around 50 people in a 12 week smoking cessation programme;
- treats around 500 people through the Minor Ailments Service;
- may provide other specialist services such as palliative care support, needle and syringe exchange and supervised administration of medicines;
- partners a local community group in a community development project such as Building the Community Pharmacy Partnership (BCPP).

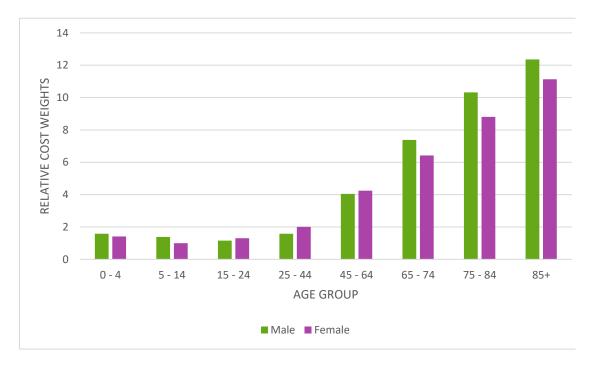
162. There are currently 532 community pharmacies in Northern Ireland, including in some of the most rural and deprived areas.<sup>371</sup> This equates to 28.4 pharmacies per 100,000 of the population. By comparison, England has 20.9 per 100,000, Scotland has 22.9 and Wales has 23.2.<sup>372</sup> In excess of 99 per cent of the population in Northern Ireland live within five miles of a pharmacy, with 80 per cent of the population living within three miles.<sup>373</sup> It has been estimated that approximately 123,000 people visit a pharmacy each day in Northern Ireland<sup>374</sup> and satisfaction levels with community pharmacy are high—according to a recent survey 98 per cent were reported to be "satisfied" with the services provided by community pharmacy and 66 per cent were "very satisfied."<sup>375</sup> Very few differences in these levels were reported between different demographics or HSC Trust areas.<sup>376</sup>

163. The average monthly dispensing volume per pharmacy has increased from 5,071 items in 2008–2009 to 6,512 items in 2018–19 $^{377}$  with £423.3 million spent on prescriptions in 2018–19. $^{378}$  The average prescribing cost per person increases with age and older males

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Bid., page 11
HSC Business Services Organisation, Family Practitioner Services Statistics for Northern Ireland 2018/19 (Revised Edition), August 2019, page 33
Ibid., page 37
Ibid., page 36
Department of Health, Making it better through pharmacy in the community, page 34
Millward Brown Ulster, Pharmacies Survey, December 2016, page 6
Ibid.
Ibid., page 34
Ibid., page 38
Ibid., page 38
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tend to have a higher prescribing cost than females. A male of 85+ will typically have a prescribing cost twelve times that of a female aged 5–14.<sup>379</sup> In 2018–19, 32 per cent of the total cost of prescriptions was attributed to the 45–64 age group.<sup>380</sup> With increases in life expectancy and major demographic shifts as the population ages these numbers are projected to further increase.

Figure 6: Prescribing cost by age and gender, 2018-19



Source: HSC Business Services Organisation, Family Practitioner Services Statistics for Northern Ireland 2018/19 (Revised Edition), Annex 4: Pharmacy Statistics, August 2019

164. Northern Ireland has the second highest number of items prescribed per head of population after Wales (though this may partially be explained by Welsh prescribing intervals being shorter than elsewhere in the United Kingdom)<sup>381</sup> at 22.4 per head of population in 2018.<sup>382</sup> This compares with 19.9 in England and 19.1 in Scotland.<sup>383</sup> However, we heard that these figures may not capture the full extent of dispensing in Northern Ireland—Community Pharmacy NI told the Committee that:<sup>384</sup>

While these [figures] confirm a higher level of dispensing in Northern Ireland, the extent is under-reported as it focuses only on ordinary dispensing, excluding multiple dispensing figures. Multiple dispensing accounts for over 13 million dispensing episodes per year in Northern

<sup>379</sup> Ibid., page 39

<sup>380</sup> Ibid.

<sup>381</sup> HSC Business Services Organisation, Family Practitioner Services Statistics for Northern Ireland 2018/19 (Revised Edition), August 2019, page 43

HSC Business Services Organisation, Family Practitioner Services Statistics for Northern Ireland 2018/19 (Revised Edition), Annex 4: Pharmacy Statistics, August 2019

<sup>383</sup> Ibid

<sup>384</sup> Community Pharmacy NI (HTH0028)

Ireland but this activity is not included when figures are compared to other parts of the UK, despite it being factored into other UK dispensing figures, generally as seven-day prescriptions.

Furthermore, for the last five years Northern Ireland has had the highest net ingredient cost per head of population in the United Kingdom—in 2018 it was £226.32 per head, 43 per cent higher than in England.<sup>385</sup>

# **Funding for community pharmacy**

165. In January 2017, prior to the collapse of the Executive, the Health Minister signed a Memorandum of Understanding between the Department of Health, Health and Social Care Board and Community Pharmacy NI to engage in negotiations aimed at developing a new framework for community pharmacy services by 31 March 2017. However, the Committee heard that though the framework has been agreed, funding negotiations had stalled. Health Minister signed a Memorandum of Understanding between the Department of Health, Health and Social Care Board and Community Pharmacy NI to engage in negotiations aimed at developing a new framework for community pharmacy services by 31 March 2017.

166. The Committee heard that community pharmacy in Northern Ireland was facing a "severe funding crisis" that was "unprecedented" and "threatening the viability of pharmacies across Northern Ireland." This had largely been due to extrapolation of the English Drug Tariff which does not take into account Northern Ireland's higher levels of community pharmacy workload or medicine procurement per head of population. 389 We were told that this was the "fundamental problem" with community pharmacy funding arrangements. 390 We were told that extrapolations have instead been carried out at a crude population level and omit funding provided to dispensing doctors in England, resulting in a distortion of baseline figures. This had led to underfunding of at least £60 million since 2011. 392

167. We heard that many community pharmacists were now dispensing medicines at a loss or without knowing whether or not they would be reimbursed at full cost.<sup>393</sup> Should this continue, we were told there would be impacts on patient safety and access to medicines with as many as 87 per cent of contractors surveyed saying they were "very worried about their own business."<sup>394</sup> Several wholesalers have written to the Department to warn that the supply of medicines will grind to a halt because of pharmacies' poor credit worthiness.<sup>395</sup>

168. In February 2015, a Cost of Service Investigation (CoSI) of community pharmacy services was commissioned by the Department of Health. It examined the cost of providing

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385 Ibid.
386 Department of Health, Community Pharmacy Services to support better health outcomes from medicines and
      prevent illness—O'Neill, 13 January 2017
     Community Pharmacy NI (HTH0028)
387
388
     Ibid.
389
     Ibid.
390
     Ibid.
391
     Ibid.
     Ibid.
392
     Ibid.
393
394
     Ibid.
395
     Chemist and Druggist, Wholesaler gives medicines supply warning as pharmacies delay payments, 12 November
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services commissioned by the HSCB and other non-commissioned services during the period 2011–12. The investigation found that the cost of community pharmacy services came to a total of £130–136 million per annum. $^{396}$ 

169. In November 2018 the Department announced an additional £11.1 million of funding for community pharmacy. This included:<sup>397</sup>

- £9 million made available up to 31 March 2020 to address immediate pressures
  within the community pharmacy network and support services for patients in
  social care settings, including extra support for pharmacies in rural locations;
- transformation funding of up to £2.1 million made available for launch of a Pharmacy First service for the winter season.

This package was in addition to a financial envelope of £104 million per annum for 2018–19 and 2019–20 to cover the delivery of community pharmacy services within contractual arrangements.<sup>398</sup>

170. Before the £11.1 million package was announced, we heard that the network was facing at least a £20 million deficit in addition to a prolonged period of underfunding.<sup>399</sup> The Chair of Community Pharmacy NI described the package of £11.1 million as a "sticking plaster approach" and that "rather than increasing the funding proposals that were under discussion during the summer the Department has responded by confirming a reduced level of funding."<sup>400</sup>

171. When questioned by this Committee on the financial pressures facing community pharmacy, the Chief Medical Officer told us:<sup>401</sup>

There is no doubt that [ ... ] there has been significant fluctuation in that profit on drugs because of costs of drugs. That has created some very significant financial challenges for community pharmacy.

With respect to the discrepancy between the findings of the Cost of Service Investigation and the levels of funding provided to community pharmacy by the Department, we were told that the CoSI "was never designed to determine what the financial envelope was like, but to inform it along with other inputs." When pressed on this issue, the Chief Medical Officer told us that:<sup>403</sup>

The Department faces significant financial constraints and many priorities across a number of budgetary areas. [ ... ] We do not have the luxury of spending money that we do not have.

172. The Permanent Secretary at the Department of Health told the Committee that he considered community pharmacy to be "a fantastic resource for the community and for

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396 PricewaterhouseCoopers LLP, Cost of Service Investigation for Community Pharmacy in Northern Ireland, May 2017, page 5
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<sup>397</sup> Department of Health, Additional funding announced for Community Pharmacy, 16 November 2018

<sup>398</sup> Ibid.

<sup>399</sup> Community Pharmacy NI (HTH0028)

<sup>400</sup> Pharmacy Business, Additional funding 'failed to address' difficulties of Northern Ireland pharmacies: CPNI, 21
November 2018

<sup>401 &</sup>lt;u>Q187</u>

<sup>402</sup> Q185

<sup>403</sup> Q189

the health and social care system" and "of fundamental importance." We were told that dialogue was ongoing between the Department and the community pharmacy network and that an agreement was "nearly there." The Permanent Secretary went on to remark: "there is a lot of untapped potential in community pharmacy. We could better utilise it."

173. Community pharmacies are a valuable healthcare resource and highly rated by the communities they serve—including some of the most deprived and rural communities in Northern Ireland—and uniquely placed to play a proactive role in the prevention and management of long-term conditions, promote wellbeing, deliver community-based healthcare and reduce pressures on General Practice. While securing a GP appointment may take days and sometimes weeks for many, community pharmacies are not appointment-led and able to provide a uniquely accessible service. Yet many are struggling to survive in the face of prolonged underfunding. The Committee recommends that the Department agree a sustainable funding package for community pharmacy based on the findings of its own Cost of Service Investigation and implement a Drug Tariff based on Northern Ireland's unique set of circumstances.

<sup>404 &</sup>lt;u>Q325</u>

<sup>405</sup> Ibid.

<sup>406</sup> Q325

# Conclusions and recommendations

#### **Transformation**

- 1. Transformation of Northern Ireland's health and social care services in line with the aims and recommendations of Bengoa and Delivering Together is needed urgently if services are to keep pace with the increasingly complex and evolving needs of an aging population. The Committee welcome funding ring-fenced for this purpose. However, the current model of non-recurrent funding over a two-year period is not suited to delivering the truly transformative and sustained change required. We recommend that, if an Executive is not in place by the end of this year, the UK Government work with the Department of Health and the Department of Finance to secure a multi-year funding settlement ring-fenced for transformation. (Paragraph 29)
- 2. Successive one-year budgets are impeding planning and investment in Northern Ireland's health and social care services. Without a long-term approach the measures needed for improving outcomes and delivering value for money cannot be taken. We recommend that, following consultation between the Department of Health, the HSC Trusts and the community and voluntary sectors to determine budget priorities, the UK Government work with the Department of Health and the Department of Finance to produce three-year minimum budget allocations. This should be implemented from the next budget. (Paragraph 37)

#### Cancer services

- 3. Cancer incidence increases with age and demand for cancer services is likely to rise as Northern Ireland's population ages. To meet this demand in the long-term a reconfiguration of services under the direction of an overarching strategy will be essential. However, in the medium-term action is needed to slow and ultimately reverse the upward trend in waiting times. The Committee recommends that the Department of Health commit to a baseline assessment to identify where gaps in the HSC workforce are contributing to delays in the diagnostic pathway for cancer patients. The Department should subsequently bring forward a strategy for closing those gaps through the recruitment and retention of an adequate workforce alongside innovations in technology and service delivery, to be published in draft by summer 2020. (Paragraph 50)
- 4. Northern Ireland is alone in the United Kingdom in not having an up-to-date cancer strategy. Without an integrated, long-term vision for improving cancer services under the direction of a well-conceived strategy, cancer services in Northern Ireland will struggle to keep pace with demand. As such, the Committee welcomes the Department's announcement that a new cancer strategy for Northern Ireland is in development. However, we recognise that many will be concerned that decisions on a new strategy are awaiting Ministerial approval. We recommend that the Department set out, in response to this report, clear timescales for its programme of work in developing a new cancer strategy and provide regular updates on progress made. This timescale should set out the key milestones where Ministerial decisions should be made. (Paragraph 58)

- 5. The Committee welcomes the Department's moves to place Northern Ireland on an equal footing with the rest of United Kingdom in opening up patient access to innovative new treatments. However, there has been a lack of updates on progress made towards realising the full raft of changes announced last year. The Department should update the Committee on what progress has been made so far and provide regular updates on further progress until such time as these changes are fully rolled out, or until the relevant Committee is constituted at Stormont. (Paragraph 68)
- 6. The Committee welcome the Department's announcement that FIT will be adopted as the primary screening test for bowel cancer. However, we are concerned that this will not be extended to men and women aged 50 and over as recommended by the UK National Screening Committee. We are not clear why this decision was made. The Committee recommends that the Department consider extending the programme to men and women aged 50 and over. (Paragraph 73)
- 7. The Committee welcome ongoing work to explore a managed strategy for introducing HPV testing as the primary test in cervical screening. However, there has been a lack of updates on progress made since the Committee questioned the Department in January. The Department should update the Committee on what progress has been made so far and provide regular updates on further progress until such time as primary HPV testing is rolled out fully, or until the relevant Committee is constituted at Stormont. (Paragraph 75)

#### Social care

- 8. The independent social care sector is struggling with competition from the low wage sector, particularly hospitality and retail, and a competitive relationship with the statutory sector. High quality social care requires a skilled and valued workforce but social care workers are often on low wages and have little scope for career development and progression. Action must be taken to make social care an attractive career choice and create closer parity between the independent and statutory sectors. The Committee recommends that the Department conduct a review of social care roles across the board to identify inconsistencies in roles, responsibilities and salaries as a step towards consolidation of the social care workforce. This review should be completed by summer 2020. The Department should further set out what steps are being taken to progress the proposals set out in Power to People for equalising pay and conditions across the social care workforce in response to this report. (Paragraph 90)
- 9. Short-term budgets are having a particularly negative impact on social care, with year-on-year uncertainty impeding the ability of providers to plan for the future and develop service innovations. As we have recommended in paragraph 36, three-year minimum budget allocations are needed for the Department of Health. This should facilitate the Department moving towards a minimum five-year partnership model with community and voluntary providers in which commissioning and investment are based on progress towards agreed outcomes. (Paragraph 96)
- 10. Social workers are spending too much time filling in paperwork and this does not represent the best use of their skills or expertise. Despite recent efforts at reducing the bureaucratic burden on social workers this continues to be a problem and is negatively impacting on both the profession and the people who depend on it. The

solution to this problem should not itself be overly bureaucratic and meaningful change could be brought about quickly and inexpensively. The Committee recommend that a task force be established with the remit and the authority to remove unnecessary and duplicated paperwork and streamline existing paperwork—though this should not be at the expense of high-quality assessments or casework. This should be completed by summer 2020. In the medium-term the Department should implement IT solutions and increase the number of administrative staff available for supporting social workers. (Paragraph 105)

#### Mental health

- 11. Despite a higher prevalence of need, the Department of Health spends a comparatively low percentage of its overall budget on mental health. Years of underfunding have meant that those in need of mental health services have struggled to access the same quality of care as those with physical health needs. The Department should increase its level of investment in mental health as a share of the overall health budget in line with recent increases in other UK jurisdictions, with the aim of reaching 13 per cent in the long-term. (Paragraph 119)
- 12. In the absence of a mental health strategy measures should be taken to ensure that Confidence and Supply funding ring-fenced for mental health is being used as effectively as possible. The Committee recommends that the Department consult widely with professionals, service users, staff, and the community and voluntary sectors on where funds would be most effectively deployed and to make this information clearly available to the public so that decisions can be properly scrutinised. Furthermore, the Department's decision to use funding to maintain existing services raises the prospect of what will happen once the deal expires. The Department should set out how it will respond to the exhaustion of additional funds for those programmes supported by the Agreement in 2018–19 and 2019–20. (Paragraph 125)
- 13. Mental health services in Northern Ireland are not delivering the model of care that Bamford envisaged. In the absence of clear lines of decision-making in mental health, Northern Ireland is in need of a comprehensive, up-to-date mental health strategy that will provide the direction necessary for developing collaborative partnerships and services that are capable of meeting the dynamic needs of service users. The Committee recommends that the Department publish the latest Bamford evaluation and use this as a first step to begin work on the mental health strategy for Northern Ireland in collaboration with the HSC Trusts, professionals, service users, staff, and the community and voluntary sectors. (Paragraph 135)
- 14. The dominant themes of the evidence we heard on Children and Adolescent Mental Health Services were of underfunding and fragmentation. The acknowledged funding gap must be closed by the Health and Social Care Board. We recommend that spending on CAMHS is brought into line with the HSCB's own recommendation of 10 per cent of the mental health budget. To ensure that funding is deployed strategically measures should be taken to better integrate the commissioning of services and develop a culture of multi-disciplinary and multi-sectoral team working. The recent review into CAMHS conducted by the Northern Ireland Commissioner for Children and Young People contained a number of recommendations based on wide-ranging consultations

with key stakeholders. We agree with the Commissioner's recommendation that a long term and sustainable 'funding and practice partnership' model be established for driving change which takes account of the investment required across all key services and sectors included in the stepped care model. (Paragraph 142)

15. Urgent action must be taken to bring down suicide rates in Northern Ireland. The comprehensive measures set out in Protect Life 2 are evidence-based and would provide clear direction and focus for tackling Northern Ireland's suicide epidemic. The Committee recommends that the Department implement the Protect Life 2 strategy as soon as the next budget is agreed. (Paragraph 147)

#### Oral health

16. Northern Ireland has some of the poorest oral health outcomes in the United Kingdom. The current oral health strategy is based on obsolete data from 2003 and does not contain any up-to-date targets for optimising services and improving outcomes. Fresh direction and impetus are needed to improve Northern Ireland's oral health. This will not be achieved with a piecemeal approach but requires an overarching, evidence-based strategy with associated targets to work towards. The Committee recommend that the Department commit to developing a new oral health strategy for Northern Ireland in collaboration with the dental profession to be published in draft by early 2021. (Paragraph 157)

#### Community pharmacy

17. Community pharmacies are a valuable healthcare resource and highly rated by the communities they serve—including some of the most deprived and rural communities in Northern Ireland—and uniquely placed to play a proactive role in the prevention and management of long-term conditions, promote wellbeing, deliver community-based healthcare and reduce pressures on General Practice. While securing a GP appointment may take days and sometimes weeks for many, community pharmacies are not appointment-led and able to provide a uniquely accessible service. Yet many are struggling to survive in the face of prolonged underfunding. The Committee recommends that the Department agree a sustainable funding package for community pharmacy based on the findings of its own Cost of Service Investigation and implement a Drug Tariff based on Northern Ireland's unique set of circumstances. (Paragraph 173)

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# Formal minutes

## Wednesday 30 October 2019

Members present

Simon Hoare, in the Chair

Gregory Campbell Kate Hoey
Maria Caulfield Ian Paisley
John Grogan Jim Shannon

Lady Hermon Sir Desmond Swayne

Draft Report (Health funding in Northern Ireland), proposed by the Chair, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph. Paragraphs 1 to 173 read and agreed to.

Summary agreed to.

Resolved, That the Report be the First Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

# Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the <u>inquiry publications</u> page of the Committee's website.

#### Wednesday 5 September 2018

Valerie Watts, Chief Executive, Health and Social Care Board and Interim Chief Executive, Public Health Agency, Dr Miriam McCarthy, Director of Commissioning, Health and Social Care Board, Dr Adrian Mairs, Director of Public Health, Public Health Agency, Paul Cummings, Director of Finance, Health and Social Care Board and Public Health Agency

Q1-58

## Wednesday 12 September 2018

Margaret Carr, Northern Ireland Public Affairs Manager, Cancer Research UK, Roisin Foster, Chief Executive, Cancer Focus Northern Ireland, Samantha Nicklin, Assistant Director of Policy and Campaigns, Breast Cancer Now, Martin Abrams, Change Delivery Manager, Prostate Cancer UK

Q59-84

#### Wednesday 17 October 2018

**Lynda Wilson**, Director, Barnardo's Northern Ireland, **Carolyn Ewart**, National Director, British Association of Social Workers Northern Ireland, **Joan McEwan**, Head of Policy and Public Affairs, Marie Curie Northern Ireland

Q85-120

#### Monday 22 October 2018

Melanie Kennedy, Catherine O'Reilly, Scott Peddie

Q121-168

#### Wednesday 28 November 2018

Dr Michael McBride, Chief Medical Officer, Department of Health (NI)

Q169-264

#### Wednesday 12 December 2018

**David Babington**, Chief Executive, Action Mental Health, **Dr Gerry Lynch**, Chair of the Royal College of Psychiatrists in Northern Ireland and Vice President of the Royal College of Psychiatrists, **Professor Peter McBride**, Chief Executive, Inspire, **Professor Nichola Rooney**, Chair of the British Psychological Society Northern Ireland

Q265-311

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# Wednesday 16 January 2019

**Richard Pengelly**, Permanent Secretary, Department of Health (NI), **Jackie Johnston**, Deputy Secretary of Healthcare Policy, Department of Health (NI)

Q312-390

# Published written evidence

The following written evidence was received and can be viewed on the <u>inquiry publications</u> page of the Committee's website.

HTH numbers are generated by the evidence processing system and so may not be complete.

- 1 AbbVie (HTH0011)
- 2 Action for Children (HTH0020)
- 3 Action Mental Health (HTH0013)
- 4 Age NI (HTH0048)
- 5 Association for Real Change Northern Ireland (HTH0002)
- 6 Association of the British Pharmaceutical Industry (HTH0024)
- 7 Barnardo's Northern Ireland (HTH0034)
- 8 BMA Northern Ireland (HTH0018)
- 9 Bowel Cancer UK (HTH0047)
- 10 Breast Cancer Now (HTH0005)
- 11 Bristol-Myers Squibb (HTH0030)
- 12 British Association for Counselling and Psychotherapy (HTH0006)
- 13 British Association of Social Workers Northern Ireland (HTH0022)
- 14 British Dental Association Northern Ireland (HTH0021)
- 15 British Pregnancy Advisory Service (HTH0025)
- 16 British Red Cross (HTH0032)
- 17 Cancer Focus Northern Ireland (HTH0015)
- 18 Cancer Research UK (HTH0017)
- 19 The Cedar Foundation (HTH0004)
- 20 Chartered Society of Physiotherapy (HTH0040)
- 21 The College of Podiatry (HTH0035)
- 22 Community Pharmacy NI (HTH0028)
- 23 Compass Advocacy Network (HTH0003)
- 24 Department of Health (NI) (HTH0050)
- 25 Inspire (HTH0045)
- 26 Macmillan Cancer Support (HTH0012)
- 27 Marie Curie (HTH0051)
- 28 Marie Curie Northern Ireland (HTH0026)
- 29 Myeloma UK (HTH0027)
- 30 Northern Ireland Assembly All-Party Group on Cancer (HTH0016)
- 31 Northern Ireland Chest Heart and Stroke (HTH0041)
- 32 Northern Ireland Commissioner for Children and Young People (HTH0049)
- 33 Northern Ireland Council for Voluntary Action (HTH0038)

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- 34 Positive Life (HTH0023)
- 35 Prostate Cancer UK (HTH0042)
- 36 Roy Castle Lung Cancer Foundation (HTH0014)
- 37 The Royal British Legion (HTH0009)
- 38 Royal College of General Practitioners NI (HTH0031)
- 39 Royal College of Nursing (HTH0037)
- 40 Royal College of Occupational Therapists (HTH0008)
- 41 Royal College of Paediatrics and Child Health (HTH0039)
- 42 Royal College of Pathologists (HTH0029)
- 43 Royal College of Physicians of Edinburgh (HTH0007)
- 44 Royal College of Surgeons (HTH0044)
- 45 The Royal College of Surgeons of Edinburgh (HTH0046)
- 46 Start360 (HTH0019)
- 47 Supported Employment Solutions (HTH0010)
- 48 Ulster Unionist Party (HTH0043)
- 49 Ulster University (HTH0036)

HC 174

# List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the <u>publications page</u> of the Committee's website. The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

Education funding in Northern Ireland: Government

Response to the Committee's Ninth Report of

#### Session 2019

First Special Report

**Second Special Report** 

Third Special Report

**Fourth Special Report** 

	Session 2017–19	
Session 2017–19		
First Report	Bombardier	HC 533 (HC 960)
Second Report	The land border between Northern Ireland and Ireland	HC 329 (HC 1198)
Third Report	Devolution and democracy in Northern Ireland – dealing with the deficit	HC 613 (HC 1589)
Fourth Report	Brexit and Northern Ireland: fisheries	HC 878 HC 1812
Fifth Report	Brexit and Agriculture in Northern Ireland	HC 939 HC 1847
Sixth Report	The Northern Ireland backstop and the border: interim report	HC 1850
Seventh Report	HM Government support for UK victims of IRA attacks that used Gaddafi-supplied Semtex and weapons: follow-up	HC 1723 (HC 2352)
Eighth Report	Changes to the Northern Ireland Renewable Heat Incentive scheme payment	HC 2070 (HC 2646)
Ninth Report	Education funding in Northern Irelan	HC 1497
Tenth Report	Welfare policy in Northern Ireland	HC 2100
First Special Report	HM Government support for UK victims of IRA attacks that used Gaddafi-supplied Semtex and weapons: Government Response to the Committee's	HC 331

Fourth Report of Session 2016-17

Electricity sector in Northern Ireland: Government

Response to the Committee's Third Report of

The land border between Northern Ireland and

Ireland: Government Response to the Committee's

Bombardier: Government Response to the

Second Report

Session 2016-17

Committee's First Report

HC 921

HC 960

HC 1198

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Fifth Special Report	Devolution and democracy in Northern Ireland – dealing with the deficit: Government Response to the Committee's Third Report	HC 1589
Sixth Special Report	Brexit and Northern Ireland: fisheries: Government Response to the Committee's Fourth Report	HC 1812
Seventh Special Report	Brexit and Agriculture in Northern Ireland: Government Response to the Committee's Fifth Report	HC 1847
Eighth Special Report	HM Government support for UK victims of IRA attacks that used Gaddafi-supplied Semtex and weapons: follow-up: Government Response to the Committee's seventh Report	HC 2352