Patient Experience

Summer 2019

Patient
Experience
Library

Editorial

"As a former cancer patient I fear getting sick again, but it's not the disease I fear, it's being lost in the system that scares me."

These words from Rachael Bull (page 3) should be heard by healthcare providers everywhere. Imagine being more afraid of the healthcare system than you are of cancer.

Patient experience is often thought of in terms of things like compassion and "patient-centred" care. Those things really matter, but both patients – and the staff who do their best to offer good care – are let down when appointments are cancelled, records go astray and "pathways" that look good on paper turn out to be impossible to navigate in practice.

Cancer Mum's story (page 4) is similar to Rachael's. As a long term carer for her disabled son, she had to fight for access to essential information from his records. Having won the fight, she found herself with a record containing hundreds of document and consultation entries that had not been indexed and so were useless. Only by organising them herself was she able to make sense of them and start using them to ensure better care for her son.

These are powerful illustrations of why we need to see things from the patient's point of view. For healthcare professionals, an overly complex system can be exasperating. For patients, it can be life-threatening.

So it is good to see the NHS Leadership Academy taking matters such as these seriously. Our third contributor, Karl Roberts, talks about the importance of patient leadership. For him, that does not mean telling patient reps what to do. It means giving them the skills and confidence to take their experiences into senior levels of healthcare organisations, helping those organisations to understand how patient experience – and healthcare systems – can be improved.

Our own take on all of this is that healthcare systems need to hear from people like Rachael and Cancer Mum. But they also need to embed individual stories in a solid base of evidence. So this edition includes our usual round-up of the latest research on patient experience and involvement.

We're always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!
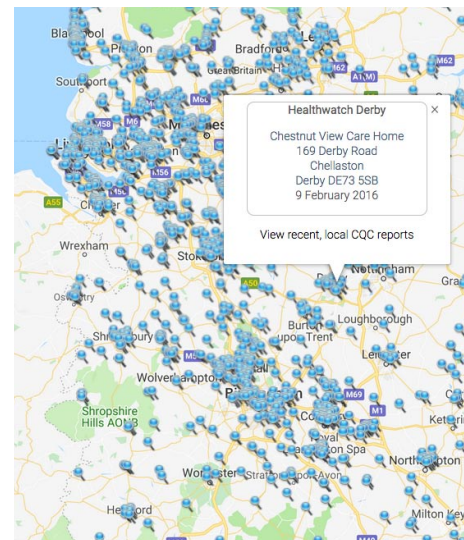
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Miles Sibley, Editor
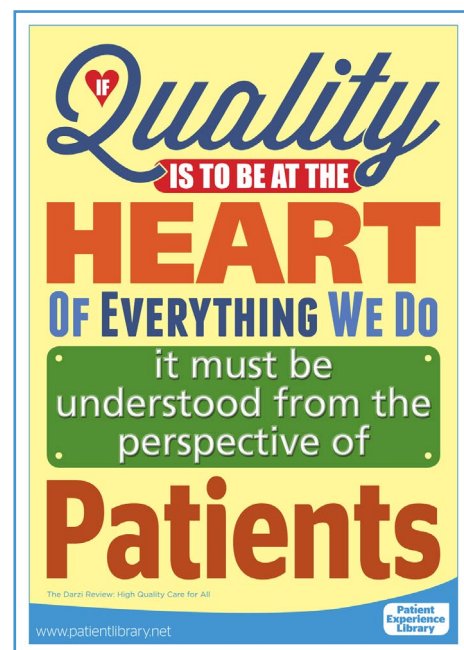
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Free resources

Our *Knowledge Maps* offer a quick and easy view of what patients are saying about healthcare services across England. Feel free to click and browse at will!

Spread the word about patient-centred care with our *posters* for offices, wards, meeting rooms and waiting areas. The quotes are from sources such as the Berwick Review and the Francis Inquiry – so as well as being visually striking they're also on solid policy ground!

Comment

Do you have opinions, insights or good practice examples that you'd like to share with our readers? Drop us an e-mail to receive our guide for contributors: *info@patientlibrary.net*

Down the Rabbit Hole

*Rachael Bull is a patient. @RachaelBull_*

Imagine you are a six year old cancer patient. You are in chemotherapy, bald and stick thin. You are taken in a wheelchair for another round of radiation. You are holding a kidney bowl because you can't stop puking. A nurse bends down and looks into your pale six year old face and says, *"You look like shit."*

That is the story of my first experience in the adult healthcare system.

Everyone talks about patient-centered care but I don't think anyone knows what it actually means. It is assumed that if I'm being treated then I'm receiving care. However, there is a whole lot more to patient care than just treatment of illness.

I see six different specialists across four hospitals in Toronto. Two have a brilliant system called Patient Portal that has all my appointments, results, and reports. Another hospital is right next door and shares some doctors, but I have no access to any of my results from this hospital.

For example, I had a smear test but never received any results so for all I know I could be running around with cervical cancer. You might say it's my job to call the clinic and get my results, but no one had that conversation with me or told me who to call – another forgotten aspect of healthcare communication.

So much of my anguish as a patient could be resolved through appropriate and meaningful communication. I have a specialist that is in the top of their field and is also the most verbally abrasive and condescending individual I have ever met. Every time I leave this doctor's clinic, I want to cry. This is not what patient-centered care looks like.

I think physicians often forget that it is scary being a patient. Two years ago, I went to see a general practitioner about a nasal infection and upon physical examination they came across my very prominent multi-nodular goitre. Then, completely ignoring my initial reason for coming, started asking questions about the goitre and then finished with, *"I wish I had a resident here to see this because you don't see this everyday"*. In that moment, I was nothing more than my condition; I was simply a fascinating medical case.

One thing I have learned is that the patient doesn't care how much you know until they know how much you care.

I am a student, but I still get appointments scheduled while I am away at university. This may seem like a simple problem – just call and change the appointment. However, I call the clinic, no one answers, I leave a message, I get a call back between one day later and never.

I have also spent more hours than I can count travelling down to appointments that were only three minutes long and could have easily been a phone call. A big step towards patient-centered care would be teaching physicians how to use technology. Telemedicine could save a lot of time for patients as well as physicians.

From 10,000 feet away you can see that the healthcare system is doing what it is supposed to do, but the closer you get the more cracks you see and the more patients you see falling through those cracks. Quite honestly, as a former cancer patient I fear getting sick again, but it's not the disease I fear, it's being lost in the system that scares me.

So how do we fix a system that has grown apart from its patients? It begins with our next generation of healthcare professionals; teaching the importance of communication, how to use their resources, and what it means to be a patient. Teach them that if they are going into medicine for reasons other than the patient, they are going into medicine for the wrong reasons. Most importantly, teach them that they are treating people, not diseases.

As a patient, it's exhausting trying to claw my way out of the cracks of a fragmented system every time I feel myself slipping and honestly, I'm running out of energy to keep clawing.

This article was originally published by *Longwoods Publishing*

Why we want our health records

Cancer Mum: *passionate, angry, frustrated, impatient, relentless and some have said simplistic.*
I use the @CancerMum Twitter handle to protect my son's identity.
My blog is here

In 2005 our teenage son was suddenly diagnosed with a rare brain tumour. Surgery left him with multiple disabilities. Over the years an unbelievable number of care providers have touched us on the worst journey a family could imagine. Only our family knew the overall picture in a complicated jigsaw of care.

As I approached a milestone birthday, I started to look to the future. As parents we will not always be here to manage our son's care with our vast knowledge of events.

Who would take over the complicated management, and who knew all the details accumulated over the years? I wondered if we could create a shareable online health account to ensure safe care in the future.

My starting point was application for full online access to my son's GP record. The application met with outright rejection. The practice said that it was not mandatory to share free text or historical letters and this would not change until they were required to do so.

Almost a year later, a Digital Champion from the Royal College of GP's who was acting on our behalf discovered that there was no electronic GP record. I had been fighting for information that didn't exist.

I had been unaware that my son's electronic records had not followed him, unaware paper records were stored off site, unaware that no significant documents had been

We are being let down. The sound of doors slamming shut is deafening.

scanned into the new electronic record, unaware that a clerk had created an incorrect summary list, unaware that access to any historical letters and consultation text would continue to be refused. Transparency and partnership working were not on the agenda.

I decided to take formal action using the Equalities Act 2010. I requested 'reasonable adjustments' to mitigate for hearing impairment and severe memory deficit. The practice agreed to facilitate full record access after a partner meeting. My son remains the only patient in a 40,000 group practice list to have this access.

Last May our son became ill quite suddenly. He was admitted in severe pain to a major neurological centre through the A&E Department. The neurosurgical team had not met him before and there was no medical record of his complex surgery and conditions. Words cannot adequately explain our terror as parents at this point.

We tried to answer questions but the stress meant that we were unable to remember details of hospitals or surgical procedures. Then we remembered the new online GP account and accessed it through an App on a phone. To our shock there

were hundreds of document and consultation entries but they were not indexed and so were useless.

Our son had urgent brain and spinal surgery and he has since recovered well. It is a situation I would not wish on any family.

We learnt from our experience and now we have a fully indexed longitudinal patient record created using the Evergreen Life App. I have transferred all relevant documents over the last fourteen years and the account is fully shareable by all members of our family.

Despite continued promises of access to all our health information by successive politicians, to people like us it seems as far away as ever. And despite years of campaigning for full GP record access by clinicians and patients alike, the new five-year General Medical Services contract leaves the choice to release historical free data with individual GP practices. What use is that to patients with complex histories? How can they manage their care? That door is closed for the next five years.

Citizens like us are still as helpless as ever standing next to that stretcher in A&E without the very basic information to save our loved one's life in a crisis.

We are being let down. The sound of doors slamming shut is deafening.

Developing Patient Leadership

In the first of a series of articles, we look at patient leadership – what it is and why it matters.

Karl Roberts
Senior Programme Lead: Experience of Care and Participation
NHS National Leadership Academy

What is patient leadership?

If you're like me, that's the kind of question that can make your heart sink a little bit. Not because it's unimportant, but because if you're not careful, it can lead to long winded debates and complicated definitions that nobody really understands.

A similar thing can happen when you try to explain why patient leadership matters. It is easy to get drawn into convoluted discussions about "impact measurement" and once again, you can end up going in circles, debating the meaning of words.

I prefer to look for examples of good patient leadership in practice. One example would be Kate Granger. It was her experience as an inpatient, feeling vulnerable and alone, that helped her to understand the importance of a personal connection with hospital staff. She set up the *Hello my name is...* campaign to encourage staff to always introduce themselves by name when looking after patients. It's a simple but effective way to help patients feel acknowledged and cared for, and it has made a powerful change to hospital culture.

Another example is Nicci Gerrard and Julia Jones, who set up *John's Campaign* for the right of people with dementia to be supported by their family carers. They were motivated by the experience of Nicci's father John, whose five-week stay in hospital catastrophically weakened his health and capacity. The important role of close family in caring for hospital inpatients with dementia is now increasingly acknowledged.

Patient leadership doesn't always have to involve campaigns. Sometimes a patient representative can help an NHS leadership team to see things that, as busy professionals, they might otherwise miss. Or they can sit on job interview panels, helping to assess candidates from a patient perspective. Reviewing policies is another task where patient insight can help to ensure relevance and usefulness.

The NHS Leadership Academy is the training ground for chief executives, board members and others who are aspiring to leadership positions within the NHS. We're now developing a national patient leadership programme with the aim of bringing on the next generation of people who can help deliver patient-centred services and personalised care. What does that mean in practice? We don't know yet!

And that's important, because it's not for us to tell patient leaders what to do. We want to provide people with the skills and confidence that will enable them to work out for themselves how to contribute effectively to NHS leadership teams.

We'll borrow from the sorts of things we already teach on courses like the *Edward Jenner* programme for foundations in leadership skills, or the *Stepping Up* programme for black, Asian and minority ethnic colleagues. And because some patient representatives are, or have been, active in senior roles elsewhere, we could also draw from our more advanced courses such as the *Nye Bevan* programme, for people who want to contribute at board level.

As we develop our patient leadership programme, we won't be writing down difficult definitions that no-one can remember. And we won't be spending time devising complicated impact measures. Instead, we'll be pointing to people like Kate, Nicci and Julia who have shown by their actions what leadership means, and who have made visible differences that anyone can see and understand.

We think there are many more patient leaders out there, whose achievements may be on a smaller scale, but still deserve to be known. If you're one of them, or if you know someone who might like to be part of our patient leadership programme, please get in touch.

karlroberts@leadershipacademy.nhs.uk

RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. Some are newly published – others are featured because they shed useful light on recent issues and developments. For full attributions, and copies of the original documents, click on the report pictures.
Do you know of a stand-out report that we should be featuring? Contact us! *info@patientlibrary.net*

CareQuality
Commission

Learning from deaths

A review of the first year of NHS trusts
implementing the national guidance

Changing the culture of care

There can be no worse experience in healthcare than the avoidable death of a loved one. The experience is even worse when bereaved relatives feel locked out of investigations, and have to fight – sometimes for years – to get the truth.

The current investigation at the Shrewsbury and Telford Hospital NHS Trust is just the latest in a series of such cases, taking in Mid Staffordshire, Morecambe Bay, Southern Health, Gosport and the Northern Ireland Hyponatraemia inquiry.

Against this background, the National Quality Board has issued guidance on learning from deaths. This report from the Care Quality Commission looks at how – and whether – NHS Trusts have been implementing the guidance.

It paints a mixed picture. Right at the start of the report, the Chief Inspector of Hospitals says, *"... we are concerned that we are still seeing the same issues persist in some NHS trusts more than two years on. Issues such as fear of engaging with bereaved families, lack of staff training, and concerns about repercussions on professional careers, suggest that problems with the culture of organisations may be holding people back from making the progress needed"*.

Happily, some Trusts have been more active in adopting the guidance, and the report gives examples, along with detailed case studies illustrating both challenges and practical solutions. These make it clear that *"there is no one factor that guarantees good practice, with enablers and barriers to implementing the guidance being interrelated. However... the existing culture of an organisation can be a key factor in trusts' implementation of guidance"*.

That question of organisational culture is important, as it clearly influenced developments at Mid Staffs and elsewhere. And on this point, the Chief Inspector sounds a warning note: *"Cultural change is not easy and will take time. However, the current pace of change is not fast enough"*.

Must we bust the trust?

"Although patients desire safe care, they are reluctant to perform safety-related behaviors when they worry it could harm the relationships they have with clinicians."

The opening statement from this paper lays bare the reality of safe practice in healthcare settings. Safety is not simply a matter of well-trained staff following the right procedures. It is also culturally influenced, depending on the quality of relationships between clinicians and patients.

This American study finds that interventions tend to focus on giving patients access to information about their own care, but generally do not attempt to influence the clinician-patient relationship. Yet, the clinician-patient relationship influences patients' willingness to engage with their safety.

In particular, patients are reluctant to engage in safety behaviour that requires them to digress from the traditional patient role by questioning or challenging clinicians' judgments. Perceptions of staff time pressure, fear of negative reactions from clinicians, and the fear of being seen as a "difficult" patient have been found to inhibit patient engagement in safety.

Sometimes, in an apparent reversal of the doctor-patient relationship, it is patients' concerns for the wellbeing of clinicians that drives behaviour. Some patients *"exhibited a desire to protect their clinician's emotional or professional needs that at times interfered with their desire to engage with their own safety"*. Others *"were reluctant to report undesirable events because of their concern over repercussions to hospital staff"*.

The authors suggest reframing safety behaviour as a co-operative act. One example is to provide a shared safety checklist with tasks assigned to both clinicians and patients. Transparently assigning tasks to both parties could help cultivate a sense of teamwork between patients and clinicians, especially if patient participation is framed as helping clinicians and contributing to the team, rather than simply ensuring personal safety.

The paper finishes with a warning about the development of new technology. Because of the importance of the clinician-patient relationship to safety, technologies should be used to supplement face-to-face communication, rather than completely replacing that communication.

The King's Fund> Ideas that change health care

Outcomes for mental health services

What really matters?

Ben Collins

March 2019
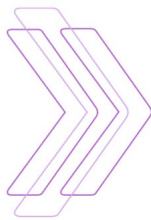
Pulling in different directions

For some years now, there has been talk of "parity of esteem" between physical and mental health. This has been defined as "valuing mental health equally with physical health" and has been seen as a way to raise standards of care for people with mental health conditions.

But how do we assess "value" in mental health services and treatments? What outcomes should we be looking for, and how would we measure them? This paper from the King's Fund makes the point that *"Even the briefest discussion with service users shatters the illusion that agreeing these outcomes will be an innocuous administrative exercise"*.

It goes on to say that, *"While there are many strong partnerships between service users and NHS services, there was also evidence of profound differences in perspective on what is important and even, at times, outright hostility and distrust between the two sides"*.

Some service users are suspicious of "narrow clinical" responses to illness, and "oppressive interventions" such as restraint and seclusion. NHS staff, for their part can feel *"accumulated demoralisation when they see the same patients in their clinics, caught up in the same cycles, struggling to make progress"*.
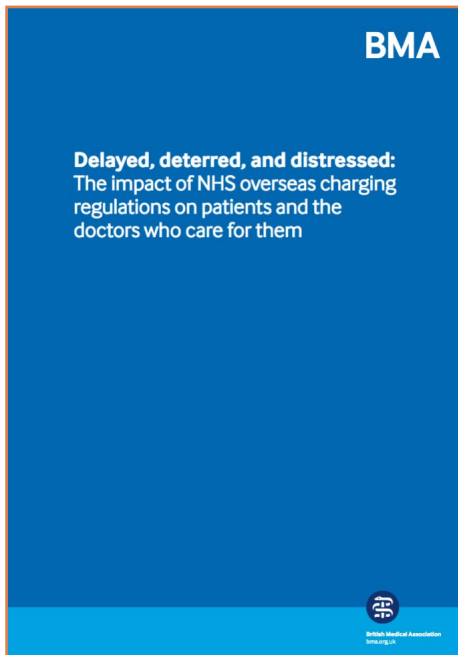
This leads to a risk that *"people with mental health problems are among the 'problem patients' of modern health care – those that seem to rub the system up the wrong way and wear professionals down with their stubborn refusal to be cured"*.

In this context, the task of defining "value" in mental health services, along with desired outcomes, is very difficult. *"The outcomes prioritised, and those discounted, inevitably reveal the degree of influence of different voices in the discussion – those around the table and those outside the room."*

The report reflects on the advantages and disadvantages of current approaches, and makes some suggestions for the future. It concludes that *"we cannot usefully direct mental health services to the dogged pursuit of particular outcomes until there is a broader consensus on which outcomes really matter"*.

And with *"service users, professionals and different professions... pulling in different directions... it is also clear that some sort of reconciliation is urgently needed"*.

BMA

Delayed, deterred, and distressed:
The impact of NHS overseas charging
regulations on patients and the
doctors who care for them

British Medical Association
bma.org.uk

A hostile environment for care

"There is now clear evidence that The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 are deterring vulnerable groups from accessing NHS treatment, threatening public health, and taking vital clinical time away from patient care."

This opener to a new report from the BMA sets the scene for a strong challenge to government on its rules for charging 'overseas visitors' for accessing NHS services in England.

The rules, introduced in 2015, are seen as part of the government's "hostile environment" for immigration. They were updated in 2017, to expand charging to community services, introduce upfront charging for non-urgent care, and require NHS services to record patients' eligibility for free treatment.

The Department for Health and Social Care (DHSC) announced a review in December 2017, less than two months after the updated rules came into force, and before some providers had had time to fully implement them, let alone assess their impact. DHSC says that the review found no evidence of the regulations deterring patients from accessing care – but it has also said that the findings of the review will not be published.

The BMA's report is based on a survey of its members, and refers to patient experience as outlined in reports such as Maternity Action's *What Price Safe Motherhood*. It finds that patients are, in fact, deterred from seeking care, *"including for treatments that are not chargeable"*. It states that *"vulnerable groups are being, and will continue to be, negatively affected by the regulations"*.

The BMA is calling for publication of the findings of the DHSC review, and for *"the introduction of safeguards to ensure that vulnerable populations are not deterred from seeking care, are able to access the care they are entitled to and that necessary treatment is not denied due to difficulty or delay in proving eligibility"*.

Rebecca Baines
Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), University of Plymouth,
rebecca.baines@plymouth.ac.uk

John Donovan
john.donovan02@hotmail.co.uk

Samantha Regan de Bere
Samantha.ReganDeBere@plymouth.ac.uk

Julian Archer
julian.archer@plymouth.ac.uk

Ray Jones
University of Plymouth, ray.jones@plymouth.ac.uk

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Services Administration Commons, Health Services Research Commons, Psychiatric and Mental
Health Commons, and the Psychiatry Commons

Questionnaires versus online feedback

Patient feedback is integral to safety and quality of care. And an NHS that aims to be person-centred needs to understand patient experience really well. Attempts to understand patient experience often involve structured questionnaires. But in a digital age, more and more people are bypassing formal surveys, and giving feedback online.

This study looks at the requirement to include patient views in regulatory processes such as medical revalidation. It asks whether questionnaires are tackling the right questions in the right way, and whether they align with the kinds of issues that patients address in online feedback. The study focussed specifically on patient experience of psychiatric care.

A key finding is that patients describe some different measures of psychiatric care quality online and use different terminology to those used in questionnaires. This may reflect the acknowledged exclusion of patients and the public in the design, administration and evaluation of patient feedback questionnaires, accentuating the importance of coproduction.

Another finding is that when psychiatric patients discuss their care online, they rarely focus on the care provided by a single psychiatrist alone. Other healthcare individuals, services, systems or processes are also described. The authors suggest that the current GMC revalidation requirement for patients to disaggregate the care provided by an individual practitioner from the wider healthcare team, service or environment is therefore unhelpful.

Timeliness matters too. Working online, patients can offer feedback as and when they need to. But, say the authors, *"The current requirement to collect patient feedback so infrequently (once every five years) sends the message, whether intentional or not, that patient feedback is unimportant"*.

The study concludes that *"The sharing of healthcare experiences online could help create desirable and dynamic transparency to the benefit of both current and future patients"*.

Staff vs culture

Just over a year ago, the Parliamentary and Health Service Ombudsman published "Ignoring the Alarms". The report described "multiple serious departures from the standards of care expected" which had led to the avoidable death of Averil Hart, a young woman who had anorexia nervosa.

As a follow-up to that report, a *House of Commons inquiry* has looked further into the failings, taking in not just the clinical care of the patient, but also the treatment of bereaved relatives who subsequently tried to find out what had gone wrong.

The Patient Experience Library submitted evidence to the inquiry, setting the PHSO's findings alongside similar findings from academic research, regulatory bodies, and other official inquiries. Our submission might make for uncomfortable reading.

We all know that there are staff right across the NHS who want the best for patients, and understand that "patient experience", in its broadest sense, is every bit as important as clinical care. But they are being let down – by Boards who won't take patient experience seriously enough, by clinicians who cannot see patient complaints as grounds for quality improvement, and by organisational cultures which inhibit change.

The Chief Inspector of Hospitals has *recently commented* on progress in learning from deaths. He said that *"...the same issues persist... issues such as fear of engaging with bereaved families"*. And he warned that *"the current pace of change is not fast enough"*.

With the publication of the Cwm Taf report (see below) and with the *Shrewsbury and Telford review* coming soon, we need absolute honesty about shortcomings in the way that patients and relatives are treated when things go wrong. Otherwise, as Bill Kirkup said in the investigation into the Morecambe Bay scandal, *"we are destined sooner or later to add again to the roll of names"*.

Listening to women and families about
Maternity Care in Cwm Taf

A report of outcomes from engagement to inform the
RCOG Invited Review of Maternity Services in Cwm Taf

Cath Broderick
Independent Specialist, Patient & Public Engagement

Cwm Taf women's voices

The *official review* of maternity services run by the Cwm Taf Health Board has now been published. It was triggered by the identification of 43 potential Serious Untoward Incidents that included stillbirths, neonatal deaths and complications of pregnancy or delivery.

This report is a record of the public engagement exercise that ran alongside the official review. The aim was to assess whether services were woman-centred, open and transparent.

The authors found that *"overwhelmingly, the women and families who came forward... spoke about distressing experiences and poor care"*. The result was *"both physical and psychological impacts on them and their families"*.

In a dismaying echo of the *Morecambe Bay investigation*, *"Women repeatedly stated they were not listened to and their concerns were not taken seriously or valued"*. In the worst cases, *"they were ignored or patronised, and no action was taken, with tragic outcomes including stillbirth and neonatal death of their babies"*.

Women's sense of not being heard was compounded by other factors including:

- Lack of access to all appropriate information, including notes

- Lack of comprehensive investigation resulting in incomplete responses to concerns

- Focus on providing responses that were formulaic and seemed to be more interested in defending the reputation of individuals and the Health Board

- Failure to apologise, causing distress

We have heard all this before – not just at Morecambe Bay, but at Mid Staffs, Southern Health, Gosport and in the Northern Ireland Hyponatraemia inquiry.

The report states that *"Already, work is being undertaken to use the lessons from the poor experience of those families... to change culture and behaviour"*. That news is welcome – but it is not enough. Bill Kirkup, author of the Morecambe Bay report said, *"It is vital that the lessons, now plain to see, are learnt and acted upon, not least by other Trusts, which must not believe that 'it could not happen here'."* So we hope that all providers of maternity services – even those that think they are doing a good job – will take the Cwm Taf review as a signal to revisit their own practice in hearing and acting on feedback from patients.

House of Commons
Committee of Public Accounts

Adult health screening

Ninety-Sixth Report of
Session 2017–19

Report, together with formal minutes
relating to the report

Ordered by the House of Commons
to be printed 1 May 2019

HC 1746
Published on 10 May 2019
by authority of the House of Commons

Screening patients out?

Health screening hit the headlines a year ago, when Secretary of State Jeremy Hunt announced that there had been a serious failure in the English breast screening programme.

Subsequent investigation found that the error was more administrative than clinical. A new service specification did not align with the IT system then in use, and was not consistently implemented by breast screening units. No-one in the Department of Health and Social Care, Public Health England or NHS England had realised.

One year on, the House of Commons Public Accounts Committee has taken another look at health screening.

Its report says that screening is an important way of identifying potentially life-threatening illnesses at an early stage. Yet the Department of Health & Social Care, NHS England and Public Health England are not doing enough to make sure that everyone who is eligible to take part in screening is doing so, and do not know if everyone who should be invited for screening has been.

The committee took evidence on the management of four health screening programmes operating in England: bowel, breast and cervical cancers and abdominal aortic aneurism. None met their targets for ensuring the eligible population was screened in 2017--18.

Performance varies drastically across the country and yet the national health bodies still do not know which specific barriers prevent certain groups from attending, meaning they cannot effectively target these groups to encourage them to attend.

National health bodies therefore run a constant risk of not knowing if all the people who should have been identified for screening have been. At the centre of this, the national oversight of screening programmes has failed patients, resulting in thousands of women not being invited for breast and cervical screenings or waiting too long for their cervical screening results.

The committee concludes that national health bodies have been too slow to recognise and respond to the problems caused, including sufficiently holding local screening providers to account for long-term failure.

Raising the equality flag

This study takes as its starting point the fact that most LGBT people aged over 50 were born when being gay was effectively illegal in the UK. Some may have hidden their LGBT identity – and from a health perspective, this could have led them to hide aspects of their own health for fear of "outing" themselves. For others, it could have fostered a reluctance to engage with health services for fear of discriminatory attitudes by health care providers.

The study looked at the health and care needs of older LGBT people across four categories: physical health and access to health care; access to social care and end-of-life care; experiences around loneliness, social isolation, and mental health; and experiences of violence.

It found that LGBT men and women aged 50+ have poorer self-rated health and are more likely to have other conditions that impact their health and wellbeing. This matters because poor self-rated health is a strong predictor of future mortality and is also used to determine healthy life expectancy and disability-free life expectancy.

There are implications for policy and practice: bodies like Public Health England are required to work toward reducing health inequalities, while local authorities have a duty to advance equality established in the Equality Act 2010. In spite of this, responses are patchy. For example, an information standard for monitoring sexual orientation is now available to all NHS organisations but use of the standard is not compulsory.

The report makes the point that specialist or targeted services rarely exist outside certain cities in which there are higher concentrations of LGBT people. But it goes on to say that while there is value in targeted/specialist services in certain areas of the country, greater effort must be made to improve the inclusivity of mainstream service provision.
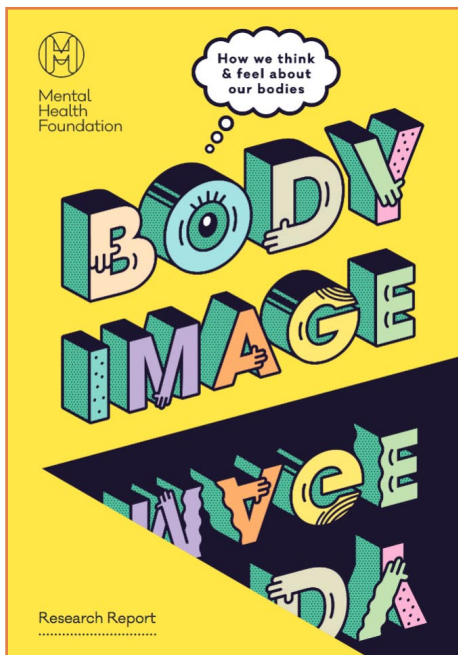
Body image matters

This report opens with the observation that *"for too many of us, our bodies are sources of shame and distress".*

It backs this up with statistics drawn from a survey of over 4,000 adults and 1,000 teenagers. These show that during the last year, one in five adults felt shame, just over one third felt down or low, and 19% felt disgusted because of their body image.

The report is clear that having body image concerns is a relatively common experience and is not a mental health problem in itself. But it can be a risk factor for mental health problems, and *"Research has found that higher body dissatisfaction is associated with a poorer quality of life, psychological distress and the risk of unhealthy eating behaviours and eating disorders".*

Body image concerns have been found to be more prevalent among people who are overweight or obese. But there are further issues relevant to body image and mental health that are specific to certain factors and experiences. These include pregnancy, the effects of long term health conditions, menopause, and ageing. Cultural differences around body ideals, and gender and sexuality also play a part.

The report emphasises the fact that developing healthy attitudes towards body image is not simply a matter for each of us individually. It considers how attitudes are shaped by advertising and social media, and recommends stronger regulation.

A section on public health suggests training for health professionals, and for the early years childcare workforce *"whose comments and behaviours are also strongly likely to influence young children's developing sense of their bodies".* Obesity campaigns should avoid creating stigma, and a body image and media literacy toolkit should be available in schools.

The conclusion calls for *"systematic action at a whole-society level to address the threats of consumerism to our mental health".*

Care deserts: the impact of a dysfunctional market in adult social care provision

Care deserts

This report, commissioned by Age UK, looks at the geographical lottery for residential and domiciliary care. It states that *"The playing field in terms of seeking care is extremely uneven from place to place and clearly, overall, this is not a market that is being managed effectively by local authorities or indeed by anyone else"*. It argues that some parts of the country are turning into 'care deserts' – areas where even if you have money to spend on care, you will be unable to get it.

The report makes the point that *"With still no sign of the Government's green paper, the social care system has been left waiting for over two years for the Government to set out its vision for the long-term sustainability of the system"*. It observes that *"There have been four independent reviews, five consultations and seven government policy papers focused on social care in the last 20 years without a meaningful change to the system"*.

The result, it says, is a social care workforce crisis, and a reduction in the number of both care home and nursing home beds, at a time of rising need. It describes a dysfunctional market for social care, and states that *"The needs of some older people must be going unmet, or they face travelling a long way to get into a care home, or their families and friends have to care for them instead. In [some] areas the care market has ceased to function and there is no care to be had"*.

The report refers to the Care Quality Commission's 2015/16 *State of Care report* which raised concerns that social care was reaching a 'tipping point'. It goes on to state that *"in some places that tipping point has now been passed"*.

The report pulls no punches about the lack of an effective political response. It states that *"while 'Brexit sucks all the political oxygen out of the air'... social care is gradually rotting away"*.

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