

My data, my care

How better use of data
improves health and wellbeing

January 2017



Preface from the Richmond Group of Charities

The Richmond Group of Charities is a coalition of 14 of the leading health and social care organisations in the voluntary sector. We work together as a collective voice to better influence health and care policy and practice, with the aim of improving the lives of the 15 million people with long term conditions we represent.



Although our health and care system often provides good care, many people experience uncoordinated services and unacceptable variation in quality and outcomes.

Importantly, we will not be able to deliver the necessary improvements to treatment, care and support without enabling safe and effective use of healthcare data.

We want people with long term conditions in the UK to live well and to experience the very best care and support because:

- **They are in the driving seat** – able to understand their health needs and how services can help them, through better self care, by sharing their records appropriately with their care team, or by being able to compare the quality of services.
- **The health and social care system understands** and responds to what matters to people living with long term conditions, based on research, audit, quality monitoring and safely governed data sharing.

It has been a turbulent few years for the health care system and the general data environment. Much has recently been proposed to improve the safe and effective flow of health care data. The Richmond Group support the fact that the National Data Guardian and their team

have undertaken a review to tackle these issues and look forward to their timely implementation by the Department of Health. We also hope that this work will signal a renewed effort to establish a balanced dialogue with the public on healthcare data, and we hope the Richmond Group will be able to play a role in this.

However, our observation is that discussions about the benefits of, and barriers to, better data use can be overly technical and fail to demonstrate what tangible benefits will be realised for people using health services. This report aims to bring these arguments back to basics:

Enabling better data use improves the health and wellbeing of people who use the NHS.

To make this argument, we present **case studies of better data use that we as leading health and care charities have facilitated**. We hope that you will find this contribution to the wider data debate useful and that together we can adopt an approach which is urgently needed that focusses on what matters: better health and wellbeing for people who need the NHS.

Lynda Thomas,
CEO Macmillan Cancer Support
On behalf of the Richmond Group of Charities

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We believe that the healthcare system must improve how it collects, shares and uses data, but that this must be done with the highest standards of data security.

Introduction

This report uses real life case studies to show why data is so critical for good healthcare and the tangible benefits which can be gained from its use. However, as well as showing the good which can come from data use, it also illustrates that the healthcare system is currently not set up to share data as a matter of course. Our case studies demonstrate the huge potential that better use of healthcare data can unlock, but also that this is currently being achieved in spite of the system, rather than because of it.

The Richmond Group shares the view that better use of healthcare data can enable individuals to manage their own health more effectively as well as allow the system to provide better healthcare through improved coordination and evidence-based improvements to services. More coordinated data use also has the potential to help us understand better the lives and needs of people living with multiple long term conditions.

There are currently significant barriers to this becoming a reality. The public and healthcare professionals continue to have understandable concerns about how and why data is being shared. The public are often unclear about the potential benefits and healthcare professionals are cautious due to unclear information governance structures. These anxieties can stand in the way of data being used to its full potential in healthcare.

There is also a lack of the data needed, sometimes because it is not collected at all or is not focussed on what matters to people with long term conditions, at other times it is difficult or impossible to access. The collection and sharing of data needs to be made routine, supported and enabled by improved digital technology.

We believe that the healthcare system must improve how it collects, shares and uses data, but that this must be done with the highest standards of data security. The views of patients and the public about their data must be listened to and respected.

We are currently at a critical point in the conversation with the general public about how their data is used. This has become a controversial issue in recent years and it is increasingly apparent that the public are confused and concerned about what may be happening to their data. Public trust in the system is imperative if we are to see the potential benefits of data use being fully realised. In order to build this trust, the bodies responsible for sharing and using data need to demonstrate that their processes are robust and secure, and state with more clarity the benefits to individuals of better data use.

Better use of healthcare data is not just a nice to have – failing to address the barriers currently preventing effective collection and sharing of data is having a real impact on quality of care and in some cases has led to unnecessary suffering. Action needs to be taken now.

If people do not understand why healthcare data is collected and what it is used for, it is easy to see why they may not be comfortable with this information being shared.

The use of data can often seem abstract and far removed from the day-to-day experiences of individuals within the NHS. It is difficult to understand exactly what is being done with this information and why.

In order to make the use of healthcare data more concrete, the Richmond Group has gathered together a collection of case studies from our member charities which illustrate how data can have a positive impact in the real world.

This report highlights some of our most impactful case studies. The examples we present demonstrate three ways in which better use of data can make a difference, for:

- 1 Me and my data**
Empowering individuals through better access to information about their own healthcare.
- 2 Me and my care team**
Providing personalised, integrated and coordinated care through collecting, sharing and using data.
- 3 Me and the system**
Improving treatment, services and support through data analysis and research.

In each case study, we outline the original problem, describe what action was taken to improve the situation and then explain the crucial role which data played.

We also included a case study that shows the harm that can be done when data is not shared appropriately and demonstrates the urgency of improving the current situation. Finally, we lay out our vision for an NHS where the case studies in this report have moved from being exceptional, to being business as usual.

Each of the case studies presented in this short report is supported and complemented by numerous other examples uncovered over the course of this project, which together make up a repository of case studies, included in the annex to this report. Collectively, these examples represent the best of data use and secure data sharing which is saving and improving lives, but also highlight the risks that come when we fail to realise the value of healthcare data.

Me and my data

Empowering individuals through better access to information about their healthcare.

Each of us has a medical record that contains information about our healthcare, but how many of us know what that record contains? Everyone has a right to see what information is being held about them and healthcare information is no exception.

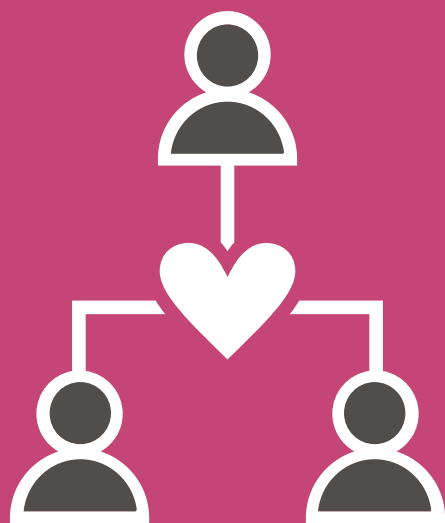
Enabling people to access their own records is empowering. It allows individuals to understand their health better and monitor and manage their conditions more easily. It encourages doctors and the people they are treating to have collaborative discussions about how to approach treatment and plan care and can allow people to include self-collected data in their record, giving a more comprehensive account of their health.

Supporting individuals to see their records also demystifies data within the NHS. It allows people to understand what information is held about them and in what format. It helps them to see how sharing their data could improve their care and makes it easier to understand the value of their information to the wider system.

The following example from Rethink Mental Illness illustrates how giving people who are using secure mental health services access to their own healthcare information has empowered them to take more control over their own recovery.

For more examples of the benefits which individuals can get from good quality data, properly shared, these additional case studies can be found in the annex to this report and on our website:

- **Accessing my medical record:** Ingrid's story
- **Helping people manage their own health:** Macmillan Cancer Support's My Organiser app



**Important benefits
which individuals
can get from
good quality data,
properly shared.**

Giving people a say in planning their care

Rethink Mental Illness's Care Planning Initiative.

The problem

Historically, within secure mental health services, people have not had a large say in the direction of their own care. Often, care plans and risk assessments are made without consulting the individual concerned, and some people have never seen their own care plan.

What action was taken to change this?

Rethink Mental Illness has been evaluating an intervention to make mental health providers more collaborative in their care planning approach. It helps individuals find their own way through a part of life that can be very confusing and difficult to manage, and to live the life they want, such as leaving secure care and moving back into the community.

This pilot project focussed on training for staff members and service users using My Shared Pathway care plans. This included keeping track of their data in a shareable and editable format by maintaining a Patient Portfolio of information.

This approach helps individuals take as much control over their recovery as possible by being involved in the process of planning their own healthcare.

Why was data important?

Allowing individuals to write, access and reflect upon their own information is fundamental to involving them in the planning of their own care. Ensuring that people being treated and staff have access to the same information and work together on care planning has been seen to have a positive impact on recovery. This can contribute towards a smooth as possible journey out of secure care and into the least restrictive environment possible.

Where can I find more information?

Evaluation report:

www.rethink.org/innovation

Overview of My Shared Pathway:

www.recoveryandoutcomes.org/my-shared-pathway/my-shared-pathway.html

Me and my care team

Providing personalised, integrated and coordinated care through collecting, sharing and using data.

As well as individuals accessing their own data, it is critical that the care teams around them also have access to up to date, comprehensive information to guide treatment.

We know that people become frustrated from having to tell their story over and over again to different healthcare professionals. We want to see a situation where, with an individual's consent, whoever is treating them can easily access the information about them that they need. This is more efficient and reduces the chances of important details being missed.

The more care professionals know about the person they are treating, the more they can tailor their treatment appropriately and integrate care between different services. Well informed staff can provide better, safer services.

The following case study from Macmillan Cancer Support illustrates how data can help care teams to understand the needs and concerns of the person they are treating, to improve their wellbeing.

For more examples of the many ways in which data, properly used, can improve people's experience of care and their outcomes, the following case studies are included in the annex to this report, and on our website:

- **Providing joined-up care by data sharing:** The Stroke Association's Stroke Coordinators
- **Wrapping care around the person:** Age UK's Integrated Care Programme in Cornwall



**Well informed
staff can
provide better,
safer services.**

Collecting the data that matters

Macmillan Cancer Support's Electronic Holistic Needs Assessment.

The problem

The current system of follow-up care after cancer treatment is not meeting people's needs, and it will not be able to cope with the expected increase in the number of people living with cancer in the UK.

Feelings of isolation and loneliness are experienced by many people with cancer but not having information about people's needs means that organisations' services and support mechanisms cannot be improved to meet them. Having an effective assessment and care plan helps to ensure that individual needs are identified and met. However, in 2014, only 22 per cent of people with cancer received an assessment of their needs and a written care plan.¹

What action was taken to change this?

Macmillan developed an electronic tool which allows someone affected by cancer to record any concerns they might have and share them with the relevant health or social care professional. This is called the electronic Holistic Needs Assessment (eHNA). The assessment can record up to 48 concerns, which cover physical, practical, emotional, family and spiritual areas. Once a person has filled in the assessment, they discuss the answers with a health or social care professional and they create a care plan together by agreeing the best way to manage their concerns. Therefore, conversations range from worries about the person's job and financial situation, to the side effects of treatment.

Why was data important?

Recording people's concerns in a care plan can identify any services or support which might benefit the person and highlight action they can take themselves to manage their situation.

As well as directly benefiting the person affected by cancer, and focusing the discussions on the person, not just their diagnosis, details can be passed onto their GP and their wider support team (with their consent) so that they have a better understanding of the person's concerns too. Also, with over 22,000 assessments having taken place, and over 17,500 care plans being put in place, trends in people's concerns can be seen in the anonymised results. Analysing these trends can reveal areas where people who are affected by cancer are not having their needs met so that organisations can improve services for people who get cancer in the future.

Where can I find more information?

Overview of the Recovery Package, including the eHNA:
www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/recoverypackage/electronicholisticneedsassessment.aspx

Information leaflet on eHNA:
be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC12957PlanningyourcareandsupportE320150302.pdf

Summary of the eHNA:
www.macmillan.org.uk/documents/aboutus/health_professionals/macvoice/sharinggoodpractice-electronicholisticneedsassessmentandcareplanning.pdf



In 2014, only 22% of people with cancer received an assessment of their needs and a written care plan.

I remember it being quite interesting because it covered a lot of things I didn't think we would talk about – emotional as well as physical needs really.

Cancer patient

The holistic approach of the project has given me a vastly improved quality of life. My diagnosis has not signified the end of my life, for me it's been the beginning. I knew very little about Macmillan but having now engaged fully with them I cannot speak highly enough of the service and of the people delivering it.



James Keating-Wilkes, who has now passed away

Me and the system

Improving treatment, services and support through data analysis and research.

The health of the population is changing and, in order for people to continue receiving excellent care, it is vital that the healthcare system changes to reflect this. The population is ageing, more people are surviving diseases which would have proved fatal in the past, and, as infectious disease is increasingly well controlled, non-communicable disease, long term conditions and multi-morbidities are becoming the conditions which challenge the NHS.

Data is vital for the people running healthcare systems to see the current situation with more clarity, to innovate and to evaluate the success of innovations. Data can also be used to understand how population health is changing and what the best ways to plan services and approach treatment are.

The following case study from The Stroke Association shows how access to healthcare data helped them to make the case for life-saving, preventative treatment.

We have collected numerous other examples that demonstrate the strength of our member charities in using data to inform system improvement. In doing this, we can support the development of an NHS which delivers better treatments, more efficiently and benefits people across the country. The following additional case studies can be found in the annex to this report, and on our website:

- **Identifying areas which need the most support:** Diabetes UK's 'Putting Feet First' Campaign
- **Caring for people after diagnosis:** Macmillan's use of data to improve care for people living with and beyond colorectal cancer in Sheffield
- **Identifying those most at risk:** Asthma UK's work with children at risk of asthma
- **Evaluating standards and improving care:** The National Diabetes Audit
- **Measuring the size of the problem:** Arthritis Research UK's MSK Calculator
- **Understanding secure services better:** Research into people who have long stays in secure care



We can support the development of an NHS which delivers better treatments, more efficiently and benefits people across the country.

Supporting healthcare professionals to raise standards

Stroke Association's targeted information offer on atrial fibrillation.

The problem

Atrial Fibrillation (AF) is a type of irregular heartbeat which can lead to blood clots causing a stroke. AF is a contributing factor to 20 per cent of strokes in England, Wales and Northern Ireland,² yet it is estimated that over a third of people with AF don't know they have it.³

If the 1.4 million people with AF in England were identified and then adequately treated with a medicine to prevent blood clots, around 7,000 strokes could be prevented and 2,100 lives could be saved every year.⁴ Unfortunately, not only is AF often undetected at the moment, but improved guidance on how to manage it effectively is not being implemented.

What action was taken to change this?

Publicly available data shows that 31 per cent of eligible people with AF are not being given treatment to prevent blood clots despite the guidance.⁵ The Stroke Association worked with Public Health England, the Royal College of GPs and the Royal College of Physicians to examine the data and understand where and how AF management could be improved.

Together they created 'AF: How can we do better?' – a free information document showing how each Clinical Commissioning Group (CCG) is performing. This has since been used to make a strong case to CCGs for the need to improve AF care.

Why was data important?

Data enabled the Stroke Association and partners to identify how many people should have been receiving treatment that could reduce their risk of stroke but were not. With this knowledge, the Stroke Association and partners were able to highlight the issue and take action, helping ensure people with AF are identified and given access to treatments; ultimately preventing strokes and saving lives.

Where can I find more information?

The NICE guidance on AF:
www.nice.org.uk/guidance/cg180?unlid=853155698201641415181

'AF: How can we do better?' document:
www.stroke.org.uk/professionals/af-how-can-we-do-better

(When) I received the 'AF: How can we do better' data... we were building a case for improving AF detection and treatment in order to reduce the rates of preventable strokes in people with AF. I was able to use the data to evidence the case for change in Hounslow and to engage partners in the work. I am now working in collaboration with other professionals to run a pilot project to improve the detection of people with AF in Hounslow.



Dr Sadia Khan, Consultant Cardiologist at Chelsea and Westminster NHS Foundation Trust

Too high a price

Healthcare data is one of the NHS's most precious resources. It allows individuals to be empowered in their own care, medical professionals to improve and tailor individual treatments and the system as a whole to learn and increase its understanding of what causes disease, how it can be prevented and how it should best be treated.

The examples in this report and its annex show the immense benefits which can come when we realise the potential of healthcare data. Unfortunately, the positive examples of data use that we have shared here are not typical across the healthcare services. The system is beset with problems, with data not being shared properly, or with the data necessary for improvements simply not being collected.

In this section, we wanted to include an example which illustrates the consequences of failing to use data appropriately. In this case study from Asthma UK, an inability to collect and share information on a single person led to the tragic and avoidable loss of a young life.

Sadly, this is not a unique example. More case studies highlighting the risks of failing to use data properly can be found in the annex to this report, and on our website:

- **Identifying the right individuals at the right time:** Breast Cancer Now's work on secondary breast cancer
- **Alzheimer's Society:** How lack of data makes it harder to improve care



Healthcare data is one of the NHS's most precious resources.

Asthma UK

How failing to link up data can have fatal consequences.

Tamara's story

Tamara Mills was a 13-year-old from Newcastle who was diagnosed with asthma when she was just nine months old.

Tamara died from an asthma attack in 2015 despite seeing GPs and attending hospital 47 times in the four years leading up to her death. The investigation into her death stated that there was 'no appreciation that each episode was a deteriorating step in her overall respiratory wellbeing' and there was no analysis of the effectiveness of the medication she was using. Each time she saw healthcare professionals, they treated the immediate problem as an isolated event and did not link up her multiple appointments and admissions.

The problem

One in 11 children in the UK has asthma. There isn't a cure for asthma and it is a long term condition which, if not treated properly, can lead to potentially life-threatening asthma attacks. The health and care system often does not join the dots between people's appointments and hospital admissions, meaning that trends in someone's health are not always noticed. This can have devastating consequences.

Why was data important?

Tamara's death could have been avoided if the system had spotted her deterioration in health by connecting the data between the 47 visits and the ineffectiveness of her treatment. Despite the frequency of her asthma attacks this sadly did not happen, with fatal consequences.

What action could be taken to change this?

Some areas of the country, such as Leeds North CCG, have begun to link data from GP practices and hospitals. This enables healthcare professionals to examine real-time data about who has had to go to hospital recently, about their asthma, and who is most at risk of having further problems. Once identified, this group of people could have their care reviewed to ensure they do not end up in hospital again because of their asthma. This approach could be introduced across the UK, led by the NHS, to ensure that people at greatest risk are identified and given appropriate treatment before it is too late.

Where can I find more information?

To find out more about the data linkage in Leeds mentioned above:

www.leedsnorthccg.nhs.uk/content/uploads/2016/07/LNCCG_J000682_Leaflet_SharingHealthcareRecords_July16_A5_WEB.pdf

To read the Coroner's report on this case:

www.judiciary.gov.uk/wp-content/uploads/2016/01/Mills-2015-0416.pdf

What needs to happen next?

The Richmond Group understands the huge potential benefits which can come from data sharing and also have experience of the profound costs when it is not used properly.

When data is used effectively in the healthcare service, it is currently often in spite of the system, not because of it. There are significant barriers in place which stand in the way of the effective collection, sharing and use of data becoming standard practice. This is particularly problematic for people living with multiple long term conditions: the effective use and coordination of data will be essential if we are to truly understand and support this group. This situation must improve, and urgently.

Digital technology needs to be improved across the NHS to facilitate data collection and sharing; data should be collected more consistently across all disease types and in all places of care; governance arrangements should be communicated clearly to medical professionals so that they feel supported to use data appropriately without endangering individual privacy. An ongoing conversation with the public is required to help increase everyone's understanding of the potential benefits of good data use and the concerns that some people have, in order to build and maintain trust in the use of data. This needs to include informing people of how their data is used and why, and what choices they have about how this happens. Crucially, we cannot demand people's trust, we need to earn it. And the best way to do so is by demonstrating the good that comes from better data use.

All this represents a significant amount of work. Improving infrastructure, changing practice and building trust are not quick to do. However, we must be ambitious. We have never before had access to the volume of data or technological power to analyse it, that we have today. We must use this opportunity to bring about improvements in treatment and care for people across the NHS.

This will require Government and leaders from across all sectors to throw their weight behind the necessary change and to tackle barriers and concerns head on.

The Richmond Group of Charities stands ready to work with the Government and everyone responsible for the use of data across the health and care system to realise the potential of this invaluable resource. We want to see a future NHS in which data is collected, shared and used, safely, effectively and routinely for individual and societal benefit with the support and confidence of the people whose data it is. We believe that if this ambitious goal is achieved, we can expect dramatic improvements in healthcare across the NHS.

The Richmond Group of Charities has compiled this collection of case studies to demonstrate the benefits of good data use to individuals and the health and care system. A small number of case studies are included in the main body of the report; the remainder are presented in this annex.

Annex: A collection of case studies

The following twelve case studies have been grouped to reflect the structure and argument of the report, according to the following broad categories:

1 Me and my data: Empowering individuals through better access to information about their own healthcare

2 Me and my care team: Providing personalised, integrated and coordinated care through collecting, sharing and using data

3 Me and the system: Improving treatment, services and support through data analysis and research

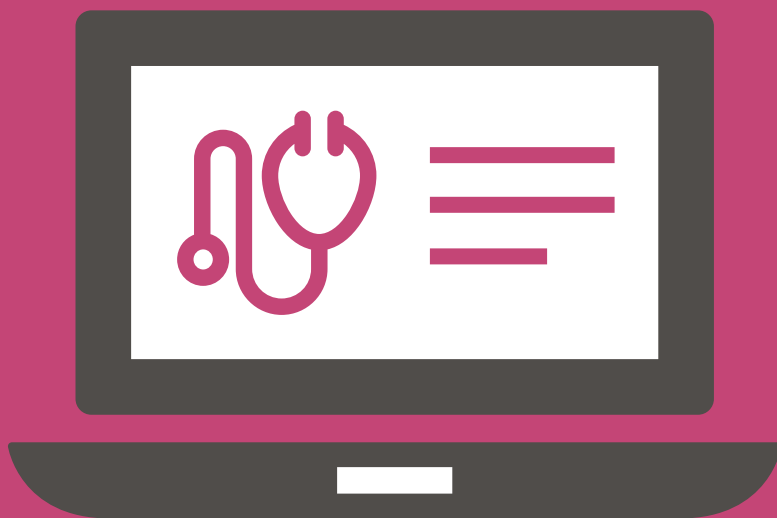
4 Too high a price: The risks we face when we fail to use data properly

1 Me and my data

The following case studies show the benefits which individuals can get from good quality data, properly shared.

19 **Accessing my medical record:** Ingrid's story

20 **Helping people manage their own health:** Macmillan Cancer Support's My Organiser app



Accessing my medical record

Ingrid's story

The problem

Ingrid Brindle has several long term conditions, meaning she has to manage a lot of information about her health, her care and her treatment.

What action was taken to change this?

Ingrid has had online access to all her GP records since 2006.

"I've had full access to my records for ten years and it's transformed how I manage my health," she says, "I have access via the practice website and on an app on my phone, with just two passwords. It helps me remember what has happened, manage my conditions safely and check I understand developments correctly. This means I can play an equal part in any discussions with clinicians, and can make decisions that are best for my health.

Other people don't know about accessing their online GP records, and both clinicians and patients don't know what the benefits are. I think patients are the most under-used resource in the NHS.

I have all my GP information including records of consultations with me everywhere I go, at home and abroad. That is absolutely terrific. It gives me confidence and I feel more independent, as I no longer have to call the practice every time I have a question. When I was in France I downloaded my two most recent cardiology letters and had them and the results to take to the hospital. Also, when visiting hospital in the UK, the consultants don't always talk to each other so I am able to fill in the gaps that are missing."

Ingrid is treated at Haughton Thornley Medical Centre. Her GP, Dr Amir Hannan, is passionate about giving people access to their medical records:

"I always encourage my patients to access their health records online. Understanding their records helps people to manage their conditions and care for themselves in a secure and safe environment."

Why was data important?

Access to her healthcare data has allowed Ingrid to be more in control of her own health. She can travel safe in the knowledge that she has all her information with her and can make sure that if she sees a new doctor, they are fully aware of her history.



I've had full access to my records for ten years and it's transformed how I manage my health.

Helping people manage their own health

Macmillan Cancer Support's My Organiser app.

The problem

It can be hard for people living with cancer to keep track of everything that's happening in their treatment and day-to-day life. This can lead to feelings of stress and anxiety, among both people caring for someone who has cancer and individuals self-managing their own diagnosis.

What action was taken to change this?

Macmillan designed the My Organiser app as a free and convenient way that people with cancer and their carers could save all the important information about treatment and care in one place. It makes it easy to record appointments, contacts and medication information, and offers useful tips and cancer information by linking to guidance and support on Macmillan's website.

Why was data important?

My Organiser allows everything someone affected by cancer needs to remember to be stored safely and conveniently on a mobile device so they can refer back to it whenever they need to, or share it with healthcare professionals and carers. From keeping track of important information and contact details to reminders about appointments or when medication needs to be taken, having everything in one place helps people living with cancer and their carers take back control of their lives.

Where can I find more information?

My Organiser app:

be.macmillan.org.uk/be/s-435-macmillan-organiser.aspx



My Organiser allows everything someone affected by cancer needs to remember to be stored safely.

Everyone is different. I'm not very good with illness, so it was a bit of a trauma to get him to have his treatment. And I used to obsess about the treatment as well. I needed to know what treatments were coming up, and I had to make sure that it was the right treatment they were giving him. The organiser we got from Macmillan helped me keep track of Sam's weight, when the next treatment was, etc. So that gave me control to a certain degree. Because I'm a bit of a control freak.



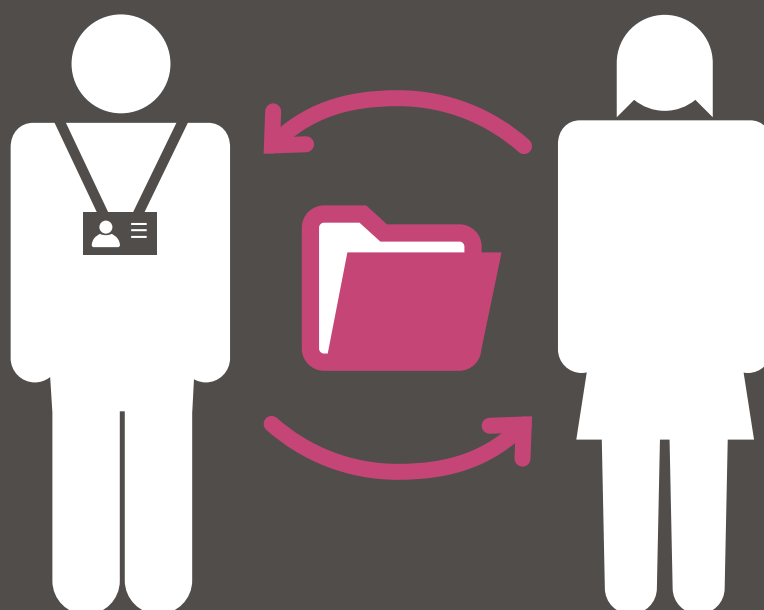
A mother talking about her son's cancer treatment

2 Me and my care team

The following case studies demonstrate the many ways in which data, properly used, can improve people's experience of care.

22 **Providing joined-up care by data sharing:** The Stroke Association's Stroke Coordinators

24 **Wrapping care around the person:** Age UK's Integrated Care Programme in Cornwall



Providing joined-up care by data sharing

The Stroke Association's Stroke Coordinators.

The problem

All strokes are different. For some people the effects may be relatively minor and may not last long, while others may be left with more serious long term problems with movement and balance, vision, swallowing, bladder and bowel control and excessive tiredness. There are also side effects you can't see: problems with communication, memory and changes to emotions and behaviour.

A stroke is immediate and is not something people can plan for. This means that when a stroke does occur, it has a huge impact – not just on the person's physical health but on their whole life – they may have to give up their job, adapt their home, they may also be entitled to benefits. At a difficult and emotional time, it can often be hard to work out what to do – Stroke Association Coordinators help with this.

What action was taken to change this?

The Stroke Association offers services across England, Wales and Northern Ireland, many of which include dedicated coordinators who work with stroke survivors to ensure they receive the care and support they need.

In Slough, since 2012, Stroke Coordinators have been an integral part of the team of healthcare professionals which supports people who have had strokes whilst in a specialist stroke unit. With the stroke survivor's consent, the Coordinator collects and shares information which enables them to gain a clear picture of the stroke survivor's needs – medical and social – to improve their recovery. The Coordinators support survivors while they are in hospital and when they leave.

Why is data important?

The access Stroke Coordinators have to information and data about individuals means they can work with the local health, social care and voluntary sector to ensure the person has access to the care and support they, their carers and families need. Ravi's story (not his real name) is just one example of this.

Where can I find more information?

Information about the Stroke Association's Life After Stroke Services:

www.stroke.org.uk/finding-support/our-life-after-stroke-services

Ravi's Story

Ravi was 56, in full time employment and fully independent when he had a stroke. His stroke left him with weakness in his right arm, hand and leg, poor balance, fatigue and some cognitive issues.

When he was released from hospital, his landlord refused to let any adaptations be made to the property and because he did not have a tenancy agreement his landlord could tell him the room was no longer for rent, making Ravi homeless. Therefore, he was discharged from hospital into an interim care bed within a nursing home for older people and later refused accommodation as he was deemed to have made himself intentionally homeless.

With Ravi's consent, his Stroke Coordinator met with the local Homeless Officer and outlined the impact the stroke had had on Ravi's day-to-day life and what his needs were to live as independently as possible within the community.

The case had to be escalated to a Housing Manager, who asked for in-depth medical information. Due to the Coordinator being a part of the team in the hospital, they were able to quickly access the medical evidence, Ravi's homeless application was approved and he was allocated a place in a supported living scheme.



Ravi's homeless application was approved and he was allocated a place in a supported living scheme.

Wrapping care around the person

Age UK's Integrated Care Programme.

The problem

Too many older people with long term conditions are not getting the personalised, integrated care and support they need to live independent lives in their community. These older people are more likely to visit their GP and be frequent users of emergency services, often with no plan in place to keep them fit and well. Of the 18.7 million adults admitted to hospital last year, around 7.6 million (41 per cent) were aged over 65.⁶ Without data it's much harder to identify the people who are most at risk; to effectively plan their care; and to share information to support them.

What action was taken to change this?

Since 2012 the Personalised Integrated Care Programme, starting in Cornwall, has now supported over 5,000 people who have two or more long term conditions and are at risk of being admitted to hospital. The Programme's approach is to improve people's wellbeing, to help re-build their self-confidence and self-reliance by providing practical support, care coordination and re-connecting them within their communities through social capital.

It does this by bringing together voluntary, health and social care services to provide personalised care and support to older people. Through a 'guided conversation' older people are central to decisions about their needs and wellbeing.

Why was data important?

The Programme relies on data in several ways. Firstly, predictive risk data stratification is used to identify older people most likely to be admitted to hospital, supporting better advanced planning for individuals' care needs.

The Programme also works to integrate different ways of recording and storing information about people so it can be effectively shared through multi-disciplinary teams. The team agree information sharing protocols and develop trust between each other so that individuals can be fully supported by the team and are not disadvantaged by a lack of data sharing.

Sharing data in this way also means individuals do not face the frustration of repeatedly telling the same story to different people. This Programme means that, with consent, the voluntary and community sectors can now access and contribute to individual NHS records. The information about what has helped people improve their wellbeing enables professionals to understand what is important for older people with long term conditions which in turn can inform commissioning decisions.

Where can I find more information?

Overview of Age UK's Personalised, Integrated Care Programme:

www.ageuk.org.uk/professional-resources-home/services-and-practice/integrated-care/our-achievements-so-far/

For me personally, I have been encouraged to look at patients where I thought their dependency levels would only increase and see that with a relatively small level of intervention, they can be encouraged back to a much lower level of dependency.



Dr Tamsin Anderson, Newquay GP

3 Me and the system

The following case studies demonstrate how better data can inform system improvement.

- **26 Caring for people after diagnosis:** Macmillan's use of data to improve care for people living with and beyond colorectal cancer in Sheffield
- **28 Identifying areas which need the most support:** Diabetes UK's 'Putting Feet First' Campaign
- **30 Identifying those most at risk:** Asthma UK's work with children at risk of asthma
- **32 Evaluating standards and improving care:** The National Diabetes Audit
- **34 Measuring the size of the problem:** Arthritis Research UK's MSK Calculator
- **36 Understanding secure services better:** Research into people who have long stays in secure care





One in two **adults** diagnosed with cancer in 2010–2011 in England and Wales is predicted to survive

10 or more **years.**⁸

I couldn't believe how easy it was to talk to the nurse and the information they gave me, how it relaxed me actually.



Person who experienced the revised care pathway in Sheffield (secondary care with the colorectal team)

Caring for people after diagnosis

Macmillan's use of data to improve care for people living with and beyond colorectal cancer in Sheffield.

The problem

There are now 2.5 million people living with cancer in the UK and it's predicted that this number will reach at least 4 million by 2030.⁷ It is important that our healthcare system provides the right support at the right time for people living with and beyond cancer and that individuals feel supported to live the life they want to. One in two adults diagnosed with cancer in 2010–2011 in England and Wales is predicted to survive ten or more years,⁸ so supporting people to live well beyond cancer is key.

South Yorkshire, Bassetlaw and North Derbyshire has one of the highest levels of people living with and dying from cancer in the country, and cancer prevalence is only predicted to increase.

What action was taken to support them?

Macmillan and a partnership of Clinical Commissioning Groups (CCGs) in South Yorkshire and Bassetlaw entered into a 'Survivorship partnership' to improve the experience and outcomes of local people living with and beyond colorectal cancer. They developed and tested a new model for aftercare, moving people from a one-size-fits-all approach directed by the health and social care system to one that offers more options for a self-managed approach.

To understand the use of the local health service and population needs, Macmillan worked with Monitor Deloitte to link and analyse anonymised healthcare data to track use of hospital services. This work helped identify the different health outcomes and cancer journeys people with colorectal cancer could experience.

Once these different likely journeys and health outcomes were identified, Macmillan was able to design and test new ways of helping people with colorectal cancer through the often complicated care pathway and help them look after themselves better.

Why was data important?

Comprehensive, routinely collected data provided a high-level view of a large number of people, enabling a cost and population analysis to be carried out.

The ability to access and analyse this type of data meant that Macmillan and partners were able to examine the clinical journey that different types of people with colorectal cancer experienced, how local services were used, and identify ways this could be improved.

The data was used to model and design new pathways of care that better meet people's needs and make efficient use of resources. Without this linked local data, local clinicians would not have been able to see how people with colorectal cancer were using their services, how they were doing and where targeted improvements may be able to make a difference.

The new care pathways have been implemented and are currently being tested.

Where can I find more information?

Information on the framework Macmillan used: www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-intelligence/routes-from-diagnosis.html

The evaluation of the Project: www.macmillan.org.uk/documents/aboutus/health_professionals/survivorshippartnership/survivorshipevaluationmay2015.pdf

Identifying areas which need the most support

Diabetes UK's 'Putting Feet First' Campaign.

The problem

In the UK, people living with diabetes are over 20 times more likely to have an amputation compared to the general population.⁹ Over 7,000 diabetes-related amputations take place in England every year.¹⁰

Amputations are expensive, reduce quality of life and can cost lives – up to 80 per cent of people die within five years of having an amputation or a foot ulcer.¹¹ Many of these amputations could be prevented if people received timely, correct foot care.

What action was taken to change this?

Since 2012, Diabetes UK has been campaigning to try to change this situation through their 'Putting Feet First' campaign.

Diabetes UK used different data sources to identify the extent to which amputations were more common in people with diabetes and to understand which areas in the UK have the highest levels of amputations. They then worked with these areas to improve the care they provide. As a result, they have been able to increase the percentage of people receiving foot examinations early on and increase the number of foot care teams.

Why was data important?

Data was a necessary condition for the campaign. Without data, Diabetes UK would have been unable to identify which areas they needed to support and challenge the most, in order to improve the care they provide. If progress continues, it is anticipated that the NHS will spend less money on amputations, fewer people will die following amputations and people will have a better quality of life than otherwise they would.

Where can I find more information?

Description of Diabetes UK's 'Putting Feet First' Campaign:

www.diabetes.org.uk/putting-feet-first

The technical evaluation of the Campaign:

www.hscic.gov.uk/media/19042/Benefits-Case-Study---Diabetes-UK-Putting-Feet-First-campaign/pdf/Benefits_Case_Study_-_Diabetes_UK_Putting_Feet_First_campaign.pdf

Data means we know about the scale of diabetes-related amputations and the variation across the country... the information has helped us to engage with local providers and show the need for better foot care.

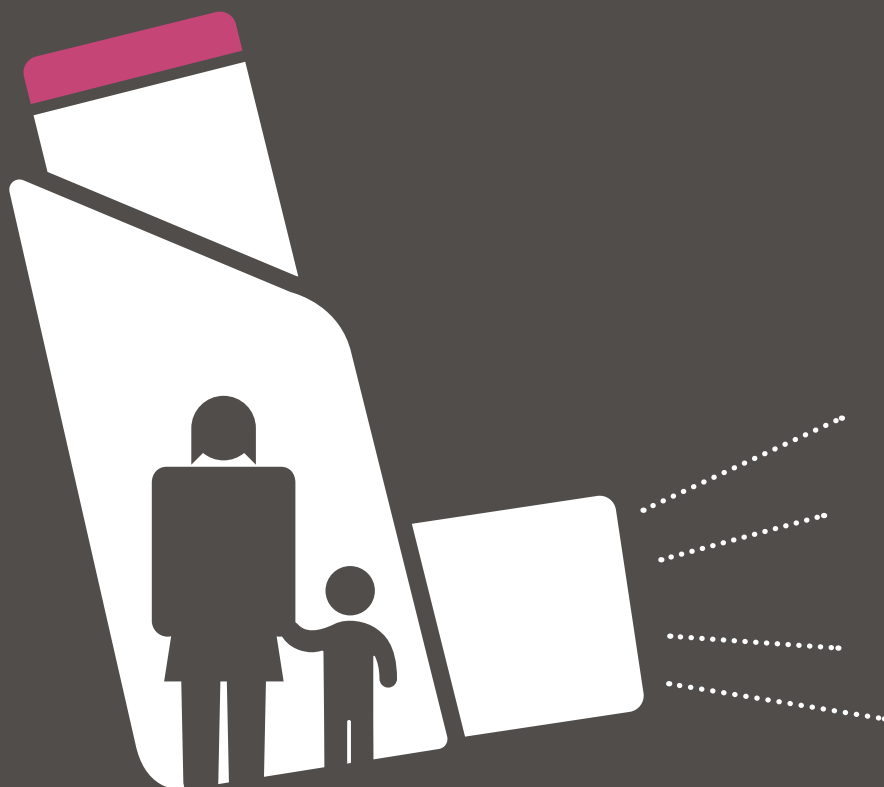


Robin Hewings, Head of Policy, Diabetes UK

**Up to 80% of
people die within
5 years of having an**

amputation

or a foot ulcer.¹¹



Every year 1,200 people
across the UK die from
an asthma attack, of
which **26 are children.**

Identifying those most at risk

Asthma UK's work with children at risk of asthma.

The problem

Every year 1,200 people across the UK die from an asthma attack, of which 26 are children. In two-thirds of cases, deaths are due to avoidable factors such as not receiving a routine asthma review.¹² It is critical that available data is used to identify people at greatest risk and prevent a potentially fatal asthma attack.

One hospital, the George Eliot Hospital Trust in Nuneaton, recognised that it needed to take action as its rate of asthma admissions was six times the England average and people treated there tended to have poor outcomes.

What action was taken to change this?

The George Eliot Hospital Trust wanted to identify children most at risk of having an asthma attack. It used a data tool developed by Health Intelligence¹³ that linked information about when children had seen their GP, attended hospital or walk-in centres, so that their records were all in one place. This required bespoke data sharing agreements between hospitals and GP practices.

This helped identify 200 children with asthma, around 200 with 'probable asthma' and nine children that could be at risk of an asthma attack because they were not being routinely called for a clinical review. Four of these children subsequently attended a one-off hospital clinic where a healthcare professional was able to assess their condition and adjust their treatment accordingly.

In addition, having a person's data all in one place enabled consultants to see their complete history and have better informed discussions with people about their needs.

Why was data important?

Without the data it would not have been possible to identify which children were most at risk of having an asthma attack and intervene with the appropriate treatment. As similar tools to assess population health are developed, such as the PRIMIS Asthma Care audit tool,¹⁴ the number of asthma attacks could be reduced, improving quality of life for people with asthma and reducing unnecessary strain on services.

Where can I find more information?

Download the Health Intelligence asthma and COPD clinical dashboard:

health-intelligence.com/products-services/long-term-conditions-intelligence/asthma-copd/

Find out your risk of an asthma attack:

www.asthma.org.uk/advice/manage-your-asthma/risk/

Contact us at evidence@asthma.org.uk for more information on this case.

By sharing data we were able to identify and focus valuable resources on the children at greatest risk, ensuring they were able to receive the treatment they needed and therefore helping to reduce asthma attacks.



Dr Hesham Abdalla, Consultant Paediatrician formerly at the George Eliot Hospital Trust

Evaluating standards and improving care

The National Diabetes Audit.

The problem

There are 3.5 million people diagnosed with diabetes in the UK and an estimated 940,000 people who have the condition but don't know it.¹⁸ Although people often receive good diabetes care, it is important to avoid unacceptable variation in quality and outcomes.

What action was taken to change this?

The National Diabetes Audit (NDA) collects information about diabetes care from GP practices and hospitals. It was introduced in 2005 and includes data recorded about all people of all ages with diagnosed diabetes in England and Wales. The NDA is used to help monitor the quality of care being provided to people with diabetes in England and Wales. Where care is falling below agreed standards in certain regions, hospitals or GP practices, the data provides the evidence needed to make a strong case that something needs to change.

Why was data important?

The data has enabled us to know whether people with diabetes are getting good care, and whether this care is consistent across the country. Since the NDA was introduced, it has demonstrated that there have been significant national improvements – with people with diabetes receiving better care, more consistent care across the country and more targets being met. However, it also reveals where more needs to be done so there can be a continuous cycle of quality improvement.

A powerful part of the Audit is its ability to link data from primary care, hospitals and mortality data. This makes it possible to see the links between standards of care and the complications of diabetes.

Where can I find more information?

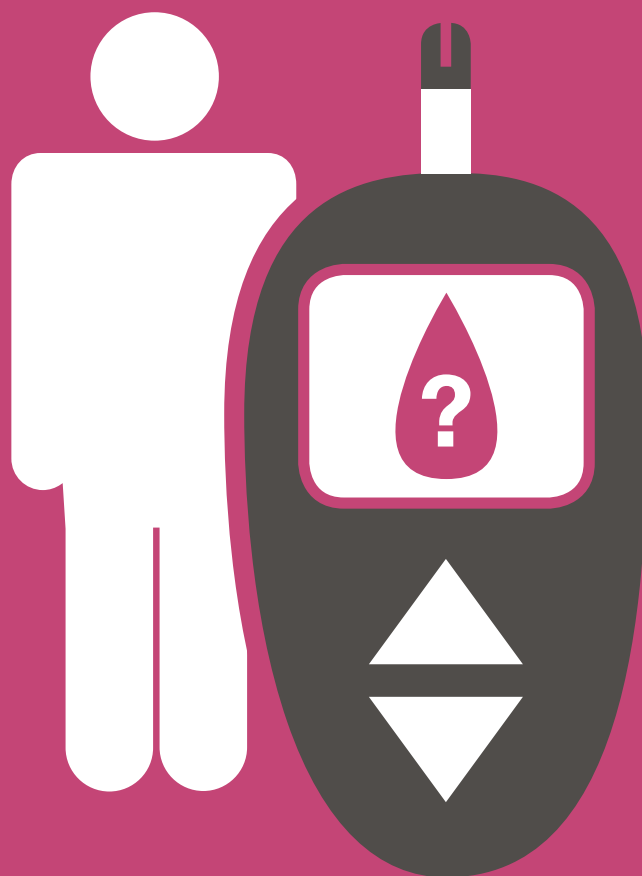
Information for people with diabetes about the NDA:
www.hscic.gov.uk/media/15870/Leaflet---Information-for-People-With-Diabetes/pdf/Patinfo_CoreAudit_leaflet_FINAL2.pdf

Easy-to-read versions of the NDA reports:
www.diabetes.org.uk/NDA-reports



Our CCG performed very badly in care processes last time and we were able to use the NDA data to highlight the problem. As a result they have appointed a diabetes lead (we were previously unable to get them to do this) and they have also supported the introduction of a Diabetes Network, having previously obstructed this.

Nene CCG, Midlands



**It's estimated that
940,000 people have diabetes
but don't know it.¹⁵**



10 million



**people live with the
devastating pain of
a musculoskeletal
condition across the UK.**

There needs to be a shift away from the perception that musculoskeletal conditions are not a priority or that nothing can be done. It is a priority for millions of people with arthritis and there are many treatments and interventions that can help.

We now have the data to show the huge burden that these conditions place on the individual and society. We want to ensure that every person living with arthritis is recognised and they receive the services that will make a tangible improvement to their quality of life.



Liam O'Toole, CEO Arthritis Research UK

Measuring the size of the problem

Arthritis Research UK's MSK Calculator.

The problem

Around 10 million people live with the devastating pain of a musculoskeletal condition across the UK. Painful musculoskeletal conditions are now the largest single cause of years lived with disability (YLDs).¹⁵ These conditions account for the fourth largest NHS programme budget spend of £5 billion in England¹⁶ and for 30.6 million working days lost each year.¹⁷

Despite this, musculoskeletal conditions have often not been included in local health needs assessments, known as Joint Strategic Needs Assessments (JSNAs). This is a missed opportunity to ensure that local services are designed to meet the needs of people living with long term, painful conditions.

What action was taken to change this?

Arthritis Research UK commissioned Imperial College London to produce – for the first time – prevalence estimates for hip and knee osteoarthritis (and also produce estimates for back pain, rheumatoid arthritis and fragility fracture risk). The data was called the Musculoskeletal Calculator (the MSK Calculator).

The data from the MSK Calculator was then used to produce an online tool with the data available by local authority, and to produce, in partnership with Public Health England, public health bulletins. This enabled local authorities to access prevalence data about musculoskeletal conditions for their locality, and to include such data in their JSNAs.

The MSK Calculator data on hip and knee osteoarthritis, and back pain (general and severe) has since been included in NHS RightCare Commissioning for Value packs.

Why was data important?

The MSK Calculator is a huge step towards filling the local information gap and is important for use in local planning of health and care, and public health services. This online tool provides health planners with the most accurate and up to date musculoskeletal healthcare data estimates.

The public health bulletins were designed to illustrate the scale of the burden of hip and knee osteoarthritis both nationally and in local areas. In addition to prevalence data, the bulletins contain risk factor information and examples of local actions which can be taken to reduce the burden of osteoarthritis in local areas.

Where can I find more information?

The data for hip and knee osteoarthritis, alongside the methods utilised to develop these datasets: www.arthritisresearchuk.org/mskcalculator

The public health bulletins for hip and knee osteoarthritis: www.arthritisresearchuk.org/arthritis-information/data-and-statistics/data-by-region.aspx

The NHS RightCare Commissioning for Value packs: www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/

Understanding secure services better

Research into people who have long stays in secure care.

The problem

Forensic-psychiatric services provide hospital care for people with mental health issues and offending behaviour. There are high, medium and low security services; typically people move from high to lower levels of security. Secure services are very restrictive for people, leading to a loss in quality of life for those spending extended periods of time there, as well as being very expensive.

What action was taken to change this?

A research project undertaken by a team at the University of Nottingham examined different data sources to try to understand the number of people who have long-stays in secure settings in England and their characteristics.

Why was data important?

Accessing the data enabled the researchers to identify common characteristics between people who have long-stays which had not been identified before. This enables a better understanding of people's situation and needs, and what needs to happen to improve the current situation.

For example, of the people identified who had long stays, most had a personality disorder, and some had learning difficulties. These conditions are often life-long and can be difficult to treat, but this project set out to assess whether high and medium secure services are the most appropriate environment for these people long term, or whether alternative settings would be more appropriate.

The next phase of activity is to develop a national strategic taskforce to examine this population currently in secure care, with a view to formulating a different approach to managing them and providing treatment.

Where can I find more information?

Description of the research project:

www.canlis.co.uk

University of Nottingham's summary of the research findings:

www.nottingham.ac.uk/research/groups/forensicmentalhealth/news/long-stay-in-fpc-findings.aspx

People with severe mental illness should be supported in the least restrictive setting, for no longer than is necessary with the most appropriate support. The Nottingham study is vitally important for the development of future secure settings, and for a system to better meet the needs of individuals who spend longer periods of time than usual within these settings. This study has moved forwards the knowledge base upon which future decisions will be made for many people, and this requires both celebration and action to ensure its recommendations are taken forwards.



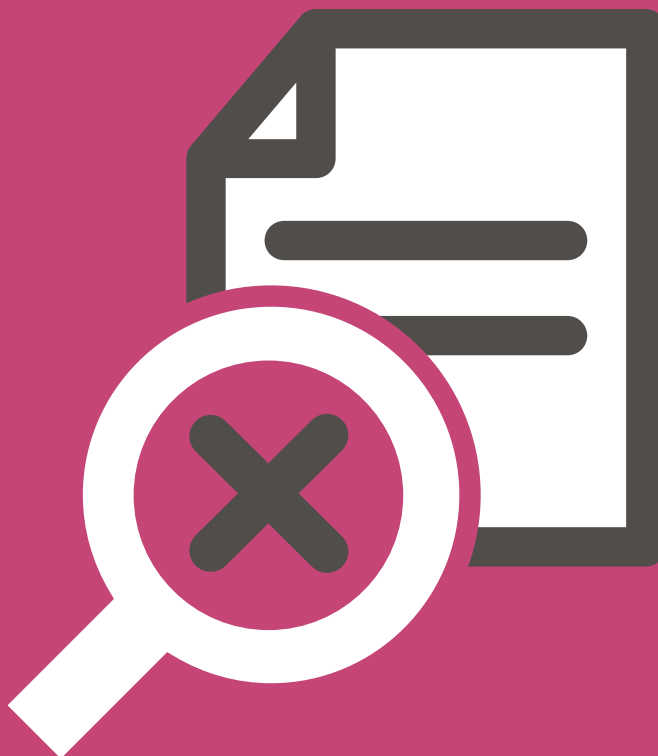
Ian Callaghan, Recovery and Outcomes Manager at Rethink Mental Illness

4 Too high a price

These case studies highlight the risks we face if we fail to use data properly.

38 **Identifying the right individuals at the right time:** Breast Cancer Now's work on secondary breast cancer

40 **Alzheimer's Society:** How lack of data makes it harder to improve care



Identifying the right individuals at the right time

Breast Cancer Now's work on secondary breast cancer.

The problem

Secondary breast cancer is breast cancer that has spread outside of the breast to another part of the body. At this stage of disease, it is incurable – around 11,500 women die of secondary breast cancer every year in the UK. However, historically data on the number of women with secondary breast cancer has not been collected and therefore we do not know how many women are diagnosed with secondary breast cancer every year. It is now mandatory to track people with secondary breast cancer through the national Cancer Outcomes and Services Dataset (as of April 2014). However, this does not always happen in practice and nationwide data is not yet available.

What action is being taken to change this?

Breast Cancer Now, together with Breast Cancer Care, has been running a Secondary Breast Cancer Pledge programme with 15 hospitals across the country since 2012. This aims to work with individuals and hospital staff to identify and implement improvements to services.

As part of this work, hospitals had to identify a sample of people with secondary breast cancer – something that took significant time and resource. Breast care nurses worked with data managers to access the hospital data system.

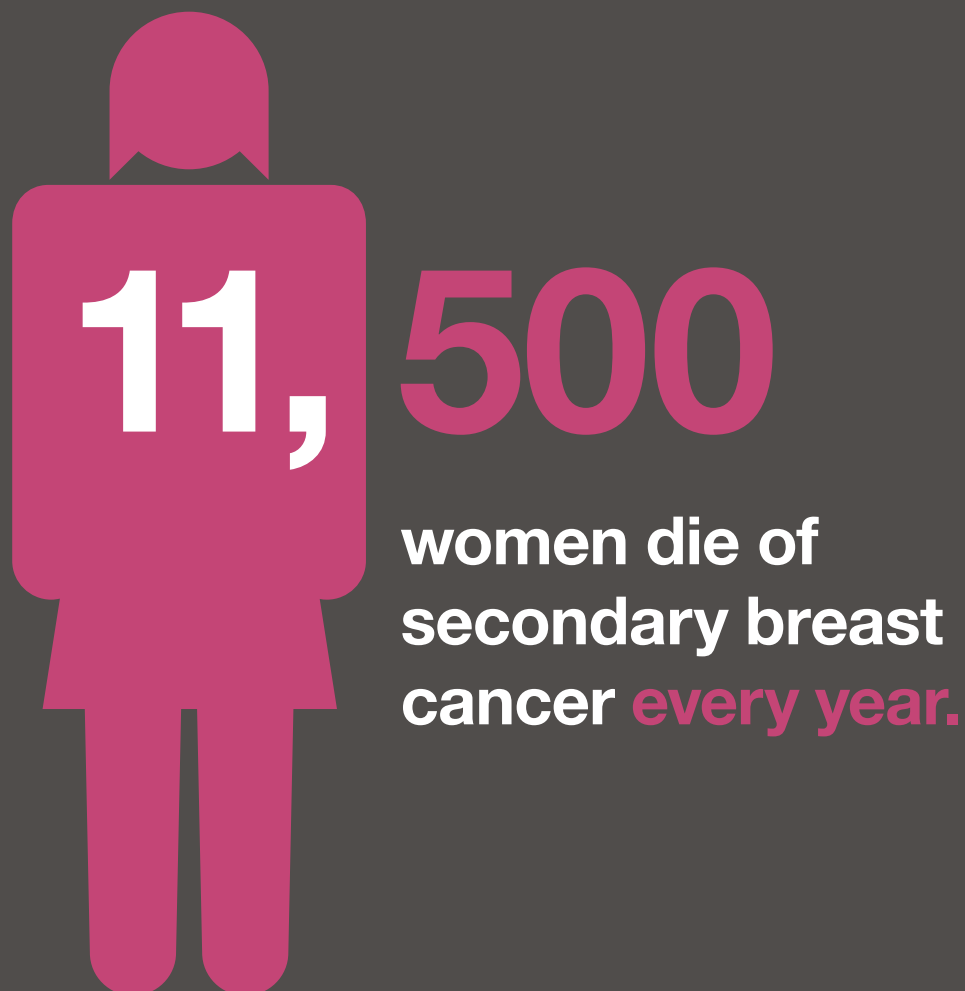
Why is data important?

Not having a complete picture of the number of people with secondary breast cancer at a hospital makes it difficult to plan for the future and show commissioners the extent of the problem, so that the right level of funding can be provided for care. People with secondary breast cancer have very specific needs, for example may need regular care to manage pain and are coping with the diagnosis of a terminal illness. It is essential that these people are identified to ensure that they have access to timely emotional and practical support.

However, one hospital explained that because the data was not captured fully, they needed to look at treatment lists and notes in order to identify people with secondary breast cancer. This was something that was common to other hospitals as well and most hospitals said that by the end of the sample identification process, they probably only identified about two thirds of the actual number of people they had. Further improvements are urgently needed to ensure that this situation improves in the future.

Where can I find out more information?

Information about the Secondary Breast Cancer Pledge: breastcancernow.org/get-involved/campaign-with-us/improving-services/what-is-the-secondary-breast-cancer-pledge



We have come up with ways to cope with this situation at our hospital and we are 95 per cent sure that we are getting all patients through that we need to see, but the system should be much more efficient, providing us with accurate information about who all of our patients are and allowing us to concentrate on our core jobs of caring for patients.



Specialist breast cancer nurse

Alzheimer's Society

How lack of data makes it harder to improve care.

The problem

By 2025 there will be 1 million people with dementia in the UK.¹⁹ At the moment there are significant gaps in the data available about dementia and, as a result, in our understanding of the quality of services people with dementia receive. Research by Alzheimer's Society found that 47 per cent of carers felt that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn't a direct result of the medical condition.²⁰

Freedom of Information requests showed that last year the average length of stay for someone over 65 in hospital was 5.5 days, whereas for people with dementia it was 11.8 days. In the best performing hospitals, the length of time people with dementia stayed was the same or only marginally longer than the length of stay for people over 65 without dementia. However, in the three worst performing hospitals people with dementia stayed between five and seven times as long as other people over 65.²¹

This unacceptable variation is currently shielded from view because hospitals are not required to share this data publicly. It is therefore not clear where the problems exist or how they should be addressed.

What action could be taken to change this?

Alzheimer's Society is calling for hospitals to publish an annual statement of dementia care, including information on length of stay so that this can be routinely monitored. This will build-on recent developments that have placed more information and data on dementia in the public domain. This includes the Dementia Intelligence Network Fingertips tool and metrics that give an at-a-glance indication of how well services are performing on dementia care. Ultimately this will help identify areas where dementia care is inadequate and needs improvement and enable more targeted regulation of dementia services in hospitals.

Where can I find more information?

Fix Dementia Care Report:

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2907

Whilst recent developments such as the Dementia Intelligence Network Fingertips tool place more information and data into the public domain, and the development of a dementia specific Clinical Services Quality Measure (CSQMs) aims to provide an at-a-glance indication of how well services are performing, there are still wide gaps in the collection and availability of data that will help us not just to monitor and understand, but also take action to improve and develop the care and support that people with dementia are experiencing.



Jeremy Hughes CBE, Chief Executive, Alzheimer's Society



million

**By 2025 there will be
1 million people with
dementia in the UK.¹⁶**

References

- 1 www.macmillan.org.uk/documents/aboutus/health_professionals/macvoice/sharinggoodpractice-electronicholisticneedsassessmentandcareplanning.pdf
- 2 www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf
- 3 www.sciencedaily.com/releases/2015/10/151017152236.htm
- 4 www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf
- 5 www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf
- 6 Hospital Episode Statistics, Admitted Patient Care, England – 2014–15, published Nov 2015
- 7 www.macmillan.org.uk/about-us/what-we-do/evidence
- 8 www.macmillan.org.uk/documents/aboutus/health_professionals/survivorshippartnership/survivorshipevaluationmay2015.pdf
- 9 N Holman, RJ Young, WJ Jeffcoate (2012) "Variation in the recorded incidence of amputation of the lower limb in England", *Diabetologia*
- 10 *Secondary analysis, by Diabetes UK, of Diabetes Foot Activity Profiles*, Public Health England, June 2015 (based on total number of diabetes related amputations 2011–2014 compiled from Hospital Episode Statistics)
- 11 Khanolkar M.P., et al. (2008). The Diabetic Foot
- 12 Royal College of Physicians, *Why Asthma Still Kills: The National Review of Asthma Deaths (NRAD)*, 2014
- 13 health-intelligence.com/about-us/
- 14 www.nottingham.ac.uk/primis/tools-audits/tools-audits/asthma.aspx
- 15 Murray C J et al. (2013). *UK Health Performance: Findings of the Global Burden of Disease Study 2010*. *Lancet* 381(9871): 997–1020
- 16 Department of Health (February 2014), 2012–13 Programme budgeting benchmarking tool
- 17 Office of National Statistics (2014). *Full report: sickness absence in the Labour Market*, February 2014
- 18 www.diabetes.org.uk/Guide-to-diabetes/What-is-diabetes/
- 19 www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341
- 20 Alzheimer's Society (2009). *Counting the cost. Caring for people with dementia on hospital wards*. London: Alzheimer's Society
- 21 OI request response from 73 of 164 acute trusts. Alzheimer's Society (2016). *Fix Dementia Care: Hospitals Report*. London: Alzheimer's Society



My data, my care

How better use of data
improves health and wellbeing

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