



20 years too soon.

Physical health: the experiences
of people affected by mental illness.



“ It seems that once you have a mental health diagnosis any physical symptoms you experience are instantly assumed to be part of your diagnosis. Once that assumption is made it is difficult to get anyone to attempt to disprove it.”

Participant at a Rethink Mental Illness Physical Health Summit, March 2012.

The context

People with severe mental illness die on average 20 years younger than the general population, often from avoidable physical illness. This group is more likely to develop preventable conditions like diabetes, heart disease, bowel cancer and breast cancer.

This shocking inequality has been a priority for Rethink Mental Illness for a number of years. We are pleased to see the recent national level commitments to improving the health outcomes of people with mental illness. Working in collaboration with healthcare professionals and guided by a steering group of people with direct experience of this problem, we want to support these commitments becoming a reality.

By raising awareness of these issues among all professionals involved in the care of someone affected by mental illness, we hope to see real improvements in physical health outcomes.

This report reflects the physical health experiences of people who use mental health services and their carers and families. We captured these experiences through a series of physical health events across the country, attended by over 200 people in Spring 2012. This report highlights not only the challenges people face in accessing timely and appropriate physical healthcare, but also puts forward recommendations made by delegates at these events.





A national policy framework

The careful monitoring of the physical health of people affected by mental illness has long been highlighted in NICE Guidelines and other examples of good practice.¹ More recently the importance of improving the physical health of people affected by mental illness has been recognised in a number of national policy initiatives:

- **Reducing premature mortality in people with serious mental illness is identified as an improvement area in both the NHS Outcomes Framework and NHS Operating Framework for 2012/13.**

- **The 2011 *No Health Without Mental Health* strategy also highlighted improved physical health as one of its six objectives. Rethink Mental Illness has been involved in the development of a practical framework for commissioners, providers and other local bodies to ensure these objectives are met. This framework is due to be published in July 2012.**

The inclusion of physical health indicators in a number of national frameworks offers a real opportunity for advances to be made in the physical health outcomes of people experiencing mental illness. This report provides insights from people directly affected by mental illness into some of the key improvements that can be made.

The role of Rethink Mental Illness

Facilitating the engagement of people affected by mental illness

As the new NHS commissioning structures take shape and patient-centred care becomes the focus of service provision, it is crucial that the physical health needs of people affected by mental illness are prioritised.

In March 2012, we responded to this new commissioning environment by bringing over 200 people affected by mental illness together with representatives from local health trusts, county councils, health and wellbeing boards, clinical commissioning groups and other key local decision makers.

Our aim was to facilitate discussion between these professionals and people affected by mental illness. We wanted those who commission and deliver local services to get an insight into the physical health issues that people affected by mental health experience. We saw this as a way to offer decision makers and people affected by mental illness the opportunity to work together to develop policies and practice that can lead to improvements in their areas.

Recognising local diversity

In order to get a picture across a number of regions, we held five physical health summits in Sussex (Brighton), Kent (Maidstone), Cumbria (Penrith), Derbyshire (Ripley) and Oxfordshire, (Oxford). Each of these summits revealed challenges and initiatives unique to their area, as well as raising themes that were common across all of the summits.

The local focus of these summits resulted in tangible solutions and follow-up actions designed with input from people affected by mental illness and local professionals. The summary reports for each of these events can be accessed at www.rethink.org/physicalhealthsummits

Developing physical health resources for professionals

We know that resources for mental health professionals are often lacking around physical health. In order to address this, Rethink Mental Illness has been involved in the following initiatives:

- The development and dissemination of the Physical Health Check tool. This tool was originally created by Dr Michael Phelan and his team at West London Mental Health Trust. It assesses and identifies key physical health concerns.

The Physical Health Check tool enables health professionals and people affected by mental illness to develop plans together so that they can address any unmet physical health needs.

- The creation of easily accessible online physical health resources, including an e-learning package. This helps to raise awareness and build confidence around supporting people's physical health needs.

A range of free materials
can be accessed at
www.rethink.org/phc

Improving physical health outcomes

This report is informed by the insights we gathered at our physical health summits. Although each event raised local challenges, there were also a number of common themes that emerged across all of the events. Poor integration of care was seen as the key challenge to better physical health. Other key areas were medication and side effects, accessing GP surgeries, physical health support in inpatient settings and the role of local community and support groups. This section addresses each of these themes in turn, highlighting the challenges facing people affected by mental illness as raised at the summits.

1. Integrated care

The physical health care of people affected by mental illness continuously falls through the gaps between primary and secondary care and between physical and mental health services. It is often unclear, both to professionals and people affected by mental illness, who is responsible for coordinating this support. This lack of integrated care manifests itself in a number of common scenarios for people affected by mental illness.

‘Diagnostic overshadowing’ is a key barrier to accessing timely and appropriate support for physical health needs. This had occurred for some of our beneficiaries when their physical symptoms were wrongly attributed to an existing mental health condition. Many people felt their concerns about their physical health were not taken seriously because of their mental illness. This discriminatory rejection of their physical health concerns has been well documented in research on stigma within the health system.² This discrimination also extended to concerns that carers may raise about the people they care for.

People are therefore caught between two parts of the system and are unable to access the support they need. Participants also commented that there was often a change in attitude among staff in physical health services once their mental illness had been disclosed. This discrimination can lead to delays in

physical health needs being addressed, which in turn can result in significant health complications. It was suggested that more comprehensive mental health training among healthcare staff would improve attitudes and ensure concerns were taken seriously.

Poor communication between primary and secondary care and between mental health and physical health services was identified as a key challenge.

This lack of communication is a barrier to both integration and continuity of care. There should be clearer communication channels between the various health professionals involved in an individual’s care, not just within a multi-disciplinary team but across all services that person engages with. Many participants at our events reported that they were constantly explaining their history to various professionals, often reliving upsetting or distressing experiences. A more integrated approach would ensure that physical health needs are fully supported.

It is crucial that this issue is treated as a priority in the new commissioning arrangements. Many of our delegates suggested that improving the physical health care of people affected by mental illness should be included in the contract requirements for commissioning new mental health services. This would help emphasise the point that physical health care is everyone’s responsibility, and not something that is just carried out in primary care.

“I ruptured my ankle tendon and couldn’t walk as a result. On a visit to hospital, the nurse looked at my medical history, and then refused to medically examine my ankle, saying I should see my Community Psychiatric Nurse.

I then had to visit another doctor to get my ankle treated. This is another example of medical staff assuming my physical health problems aren’t really there and are just manifestations of anxiety.”

Participant at a Rethink Mental Illness Physical Health Summit, March 2012.

“My son was a fit and active teenager who enjoyed many sports at school and would walk 15 miles easily. He was over 5ft 10 and weighed less than 10 stone. At 19, he was admitted to a psychiatric unit and given Haloperidol which increased his appetite.

He was then diagnosed with schizophrenia, and given Olanzapine, after which the weight piled on. He doesn't eat more now than he used to but weighs several stone more. Now, at the age of 33, my son has diabetes and has been prescribed statins.

We all wish we had known the potential side effects of Olanzapine, and that another drug with less drastic drawbacks could have been available.”

Participant at a Rethink Mental Illness Physical Health Summit, March 2012.

KEY CHALLENGES

Physical health concerns not being taken seriously because of a mental health diagnosis.

Delays in treatment as people are caught between mental health and physical health services, which can exacerbate physical health problems.

Lack of communication, both between primary and secondary care and between mental health and physical health services.

2. Medication and side effects

Many people who attended the discussion groups said that the side effects of medication are not always fully explained. Insufficient discussion about the risks and benefits of medication disempowers people as they are unable to make an informed decision. If people do not know the potential side effects of their medication, it is difficult to be proactive in addressing them. The very rapid weight gain associated with some antipsychotic medications was highlighted as particularly distressing for individuals and their carers.

Carers also reported that this lack of information means they often do not know what they should be looking out for and monitoring. Comprehensive information about medications and side effects should be available in an accessible format. This information should then be the basis of discussions around treatment choices between professionals and people affected by mental illness.

There are recommendations in both the bipolar disorder and schizophrenia NICE guidelines referring to the importance of involving people in decisions about their medication. Despite this, a recent Care Quality Commission (CQC) survey highlighted that over a quarter (28%) of people had not had side effects explained to them.³

Rapid weight gain, a common side effect of many antipsychotic medications, was seen as a key issue among delegates at our events. Inadequate monitoring of weight and a lack of support in trying to counteract weight gain were major concerns. Many people also reported that medication reviews, which would be a time for these concerns to be addressed, were infrequent.

People should be offered regular medication reviews, including discussions of side effects and alternatives to medication. A medication review should also support people to explore reducing dosage or coming off medication altogether. Several delegates described this as a taboo subject and said that practitioners are averse to 'positive risk taking'.

KEY CHALLENGES

People affected by mental illness, and those who care for them, are given inadequate information about medication. This means informed decisions, fully taking into account the risks and benefits, can not be made.

The monitoring of side effects is irregular and inadequate.

People are not frequently offered medication reviews.

3. Reasonable adjustments in GP practices

The difficulty in accessing GP appointments and other primary care services was raised repeatedly at our health summits. Short appointment times, stressful waiting areas and the lack of proactive follow up if appointments are missed were seen as key problems.

The booking system for many GP surgeries also disadvantages people affected by mental illness as it requires people to call early in the morning. This can be difficult if people are on medication that can affect sleeping patterns and energy levels.



We also had feedback from people who are unsure about what they should be raising with their GPs. This was particularly true around medication side effects, such as weight gain.

One GP surgery in Cumbria had been proactive in addressing some of these challenges. It offered patients who frequently attended the surgery a longer appointment time so that a range of health concerns could be discussed. This successfully reduced the number of appointments these patients consequently made. Delegates felt this was a good way of addressing more complex health needs and ensuring adequate support was offered.

There also appeared to be a low awareness of the needs of people affected by mental illness in primary care settings. As well as GPs themselves, GP practice staff were identified as a key audience who could benefit from mental health awareness training. Receptionists are often the first contact point for people in a GP surgery, whether in person or over the telephone. They could therefore play a significant role in making the experience less distressing and more accessible for people affected by mental illness. Without this move to make GP surgeries more accessible, people could be missing out on vital physical health support.

It was considered very important that people with direct experience of mental illness have the chance to present their experiences to GPs and other health professionals. A local service user forum in Kent had organised and delivered training in GP surgeries and had felt it was successful, although this was mainly attended by receptionists.

Very few delegates were aware of ways of being involved in their GP practice's Patient Participation Groups (PPGs). More proactive promotion of the PPGs to vulnerable or marginalised groups could result in GP surgeries being better equipped to handle the needs of these groups.

KEY CHALLENGES

Many people faced problems accessing their GP surgeries for a range of reasons. These surgeries often did not have adjustments in place for people affected by mental illness.

There can be low awareness of mental health among GPs and practice staff.

“I ask for so much support with my mental health I feel like I am taking up too much time to raise physical healthcare concerns, especially when appointments are so short and can be difficult to get. I feel I have to prioritise and mental health wins.”

Participant at a Rethink Mental Illness Physical Health Summit, March 2012.

4. Physical healthcare in inpatient settings

Access to physical health support within psychiatric inpatient services was raised as a particular concern at the summits. Even in Trusts where there are areas of good practice among community teams, inpatient settings appear to be particularly restricted in what they offer. Physical activity is often limited, smoking rates are high and many people commented on the poor nutrition of the food provided. There appears to be little proactive health promotion in these settings.

One carer from Oxfordshire explained that her son had opted for prison rather than a secure ward as the environment was much more stimulating, providing better opportunities for exercise and health advice than the wards. A number of people reported not being offered routine screenings while on inpatient wards and there were concerns about the impact this could have, particularly on long term patients.

Access to smoking cessation services in inpatient settings was described as being limited. Delegates commented that this was a good time to offer people intensive support if they wanted to quit smoking and that it was a shame this was lacking in many wards. Although there are specific complicating factors around smoking cessation and mental illness, delegates suggested that more specialist services should be developed to address high smoking rates.

KEY CHALLENGES

There needs to be improvements in ongoing and preventative physical health care for long term inpatients.

Smoking cessation services with specialist mental health expertise should be available, particularly in inpatient settings.

5. Accessing local services and support groups

People felt uninformed about physical health services and support groups that are available to them and that there was a role for health professionals to signpost to these. In a lot of areas there are good local initiatives around physical health, but people often find out about them by chance and not in a structured way.

This signposting could be a crucial role for Public Health teams going forward. If information was available and accessible, this could support both health professionals (in terms of referrals) and people using mental health services. In Derbyshire, a community services directory had recently been launched which listed details of sports and peer support organisations. This was seen as a very useful initiative by delegates as it was an easy reference point.

The importance of peer support was raised in a number of the summit discussions and it was felt that it was a model that could be of benefit to a number of people affected by physical health issues. In fact many people said that the majority of the information they had on side effects, physical health etc. to date had come from these more informal support networks than from healthcare professionals. However there was also an acknowledgement of the difficulties these groups can face in becoming established and the fact that there is not a support group available in every area. It is therefore crucial that there is improved provision of information from healthcare professionals to people they are in contact with rather than over-reliance on other channels.

KEY CHALLENGES

Local community services and support groups are often not widely advertised and people are unsure where they can access help.

Peer support groups, which are an invaluable source of support and information, are often inconsistently available and under-resourced.



Next steps: towards better integration of care

The dominant theme across all of these discussions was the importance of integrated primary and secondary care. The experiences of those affected by mental illness show that this lack of integration was at the root of many of the challenges they faced accessing support. Without this holistic approach, people's physical health needs will continue to be overlooked or assumed to be someone else's responsibility. Although pockets of good practice undoubtedly exist around integration, people affected by mental illness still face significant health inequalities and it's costing them their lives.

Given the strength of this feedback from our members, Rethink Mental Illness hopes to develop a collaborative care charter around physical health. A charter could outline key principles of integrated care across primary and secondary care and help improve outcomes by ensuring that people are offered the physical health support they need. It would serve as a reference point for health professionals and people affected by mental illness, outlining roles and responsibilities around physical health care.

We plan to work in partnership with key professionals across primary and secondary care and people with direct experience of mental illness to develop this charter. We see this report as the start of this engagement process. By bringing together these different perspectives, we hope to create a charter that builds on existing practice and helps to address some of the key challenges raised in this report.

As this issue increasingly becomes a national priority, it is vital that practical and constructive solutions can be found to improve the experience of millions of people living with mental illness.



Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For 40 years we have brought people together to support each other. We run services and support groups across England that change people's lives and we challenge attitudes about mental illness.

- We have 250 services which help people live independently, make the most of their lives, make their voice heard, cope in a crisis without hospital and find out about their rights. We may have a service near you, go to www.rethink.org/services to find out.
- We have 150 support groups where people can share experiences and find understanding. We may have one near you. Go to www.rethink.org/groups to find out.
- We campaign to improve people's rights to care and put an end to stigma and discrimination. www.rethink.org/campaigns
- We have a network of thousands of members who feel part of a movement to improve the lives of people affected by mental illness. Join us today www.rethink.org/join
- We provide reliable information on topics from medication to housing rights. Go to our website www.rethink.org/information or call 0300 5000 927.
- We have specialist advisors who help with benefit problems, debt, access to services, medication and rights under the Mental Health Act. Call 0300 5000 927, Monday to Friday, 10am to 1pm or email advice@rethink.org
- Join our online community 'Rethink Talk', where people connect to others with similar experiences www.rethink.org/talk
- We train teachers, the police, and everyone who needs to understand mental illness better. Call 0300 5000 927 to find out more.
- Our research gives new perspectives on mental illness and improves the evidence base. Visit www.rethink.org/research



Rethink Mental Illness is a partner in:





**Leading the way to a better
quality of life for everyone
affected by severe mental illness.**

For further information
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