CONSULTATION QUESTIONS

Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but **we want to consult on:**

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes;
- Whether there are any gaps in the key challenges identified;
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

About Roche – why we are responding to this consultation

Roche is a leading manufacturer of innovative medicines with expertise in a wide range of medical conditions spanning both primary and secondary care. We collect and analyse intelligence on emerging issues and challenges to help inform health service delivery in Scotland, and work with partners to promote initiatives designed to improve the quality of care and experiences of patients.

Roche is committed to investing in research into treatments for disorders of the central nervous system (CNS), recognising that these represent some of the greatest areas of unmet medical needs. At present we have ten novel compounds in development for disorders of the CNS, including schizophrenia, which we hope patients will be able to benefit from in the near future.

We are committed to working in a constructive partnership with NHSScotland, as well as health policymakers and stakeholders, and we are pleased to have the opportunity to provide comments on the Mental Health Strategy for Scotland. Roche is particularly interested in the way that services and support in Scotland are planned and delivered to best meet the needs of patients with serious mental illness, and our response is focused accordingly. In summary:

1. Roche welcomes the overall structure of the Strategy. It builds on the positive foundation established by the Scottish Government to date (*Delivering for mental health* and *Towards a mentally flourishing Scotland)* and provides a supportive framework to drive mental health improvement and the development of high quality mental health services at each stage of the patient journey.

2. The Strategy could be strengthened through clear differentiation of the needs of individuals at risk of experiencing a range of mental health problems in their lifetime. For example, services will need to respond very differently for people living with anxiety or mild to moderate depression, and for those experiencing psychosis or other symptoms associated with serious mental illness. The Strategy should provide a clear roadmap for achieving improvements in the outcomes and experiences of people with different types of mental illness, while improving productivity and delivering efficiencies where possible.

3. Further actions to be prioritised include:

- Setting out how services should address the multi-disciplinary needs of patients, across the entire patient pathway, and coordinate a range of social, psychological, and pharmacological interventions
- Driving the implementation of good practice work undertaken to date (eg SIGN guidelines on psychosocial interventions in the management of schizophrenia, integrated care pathways for mental health) and the roll-out of early intervention pilots (NHS Lothian, NHS Greater Glasgow and Clyde)
- Addressing the cross-cutting impact of serious mental illness on social and welfare policy.

Interventions to address persistent, negative symptoms of mental illness can support social outcomes (eg participation in paid or unpaid work) and can therefore generate efficiencies in other areas of public spending

- Further action is needed to improve data collection building on the Scottish benchmarking project. This would facilitate greater oversight of services, and the increase the momentum to drive change. In particular data collection should cover the burden of illness, as well as new indicators for service delivery, treatment and care as well as patient outcomes and experiences

Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes. An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

Question 1: In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes.

- In a tough economic climate, public sector budgets are increasingly contested - we need further action to ensure that investment intended for mental health services is safeguarded and not diverted to other areas. There must be a clear signal from the Government that appropriate levels of funding are made available to support:

- Mental health prevention, awareness and anti-stigma campaigns
- Access to psychological therapies for people with all types of mental illness
- Timely, specialist services that support the complex and long term needs of patients with serious mental illness such as schizophrenia

- Further work is needed to support the implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003 (recognised as an exemplary piece of mental health legislation). This would ensure that Intensive Psychiatric Care Units (IPCUs) are able to deliver high quality, personalised assessments, and timely treatment and care for people with serious mental illness including those who have experienced psychotic episodes. Targets and incentives should be introduced for NHS Boards to improve standards of care and promote effective recovery.

- Roche supports the implementation of best practice guidance for patients with serious mental illness (schizophrenia alone affects 51,000 patients and their carers in Scotland)[i] and effective oversight of the way that local authorities are fulfilling their duty to provide services to support people with mental illness and support their social development.

- It is important to ensure that the personalisation agenda and initiatives to enable self-directed support are attuned to the needs of people with serious mental illness. Less than 3% of direct payment packages in 2009 were for people with a mental health problem[ii]. This will take time and commitment and a cultural shift in the way that patients with serious mental ill health are managed, for example by:

- Entering into an honest dialogue about treatment, including discussing strategies to support adherence to pharmacological treatments, and participation in psychological therapies
- Understanding the different characteristics of mental illness which may hamper effective health and wellbeing (eg in schizophrenia, 'negative' as well as 'positive' symptoms)

- Understanding what constitutes 'recovery' and good quality of life for people with serious mental illness, and what supported choices they would like to make

Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes. Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

Question 2: In these situations, we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

- Steps to improve mental health in Scotland and reduce the impact of serious mental illness could be achieved through a more co-ordinated approach to policy development. The benefits of effective management of mental health to society and the econony should be recognised and appropriate interventions should be incentivised. National indicators should be developed to support the integration of health, social and welfare policy and more effective joint working across local authorities and health boards. Investment on effective treatment/interventions in health can help to recoup costs in other areas of public spending, by enabling service users to:

- Participate in some form of work whether paid or voluntary, full or part time
- Achieve personal and/or clinical recovery, management of mental ill-health, and development of coping mechanisms and life skills
- Improve social mobility, and participation in community life
- Improve overall wellbeing and health outcomes through better management of physical illness

- A national level programme to support the development of the health and social care workforce (in primary, secondary and tertiary care settings) could help to engender a human rights, person-centred approach to care. This would ensure that the health service addresses both pressing, acute symptoms of mental ill health, and the holistic, long terms needs of each individual (such as maintaining personal relationships and social functioning). It would also help to improve appropriate, early diagnosis which can in turn support long term prognosis.

- Roche welcomes the Scottish HEAT target on psychiatric inpatient readmissions, however there is a need for further targets to drive prompt referral to treatment and specialist services. Targets already exist for CAMHS and for access to psychological services so additional targets are need to support adults with mental ill health which cannot be managed through psychological interventions alone.

Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

Question 3: Are there other actions we should be taking nationally to reduce self harm and suicide rates?

- It is critical that efforts to reduce suicide rates are effectively targeted. Interventions to reduce suicide arising from anxiety and depression may be different from those required to support those at risk of suicide due to other types of chronic and disabling mental illness (which may involve episodes of psychosis). Often there are common factors across different conditions that can lead to suicide such as the collapse of personal relationships and loss of job and home, and drug or alcohol misuse.

- Around 10 per cent of people diagnosed with schizophrenia will die an unnatural death, usually suicide, compared to a suicide incidence in the general population of 1 per cent, and almost 50% of people with schizophrenia will attempt suicide in their lifetime[iii]. Interventions which can reduce the risk of suicide include effective support in the community, financial security, safe accommodation and meaningful occupation in day centres and sheltered work settings for those without paid employment. The ability of some schizophrenia patients to benefit from these interventions can depend on the extent to which positive and negative symptoms are managed.

- As many suicides take place in a hospital setting – particularly in-patient psychiatric wards, staff need to be fully trained in risk assessment and prevention, and should take a holistic approach to a person's treatment and care.

Question 4: What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

- Roche notes that Scotland is recognised as a world leader in anti-stigma campaigns[iv].

- Stigma can negatively affect the outcomes of people with mental ill health. For example, it can:

  - Result in delays to diagnosis or patients never receiving an accurate diagnosis
  - Prevent people from seeking appropriate advice and support which can lead to their condition deteriorating
  - Cause widespread misunderstanding of the range symptoms associated with particular conditions, and how people with mental illness can be best supported to manage a range of acute and persistent symptoms. In turn this can lead to discrimination in a range of settings

- Building on the progress achieved by anti-stigma campaigns for more common types of mental ill-health, Roche calls for further steps to de-stigmatise more severe forms of mental illness. In these cases it may be harder for members of the public to empathise with patients or relate to particular symptoms (eg delusions and psychosis). These symptoms have historically evoked negative reactions due to a lack of understanding, stereotyping and sensational reporting in the media.

Question 5: How do we build on the progress that *see me* has made in addressing stigma to address the challenges in engaging services to address discrimination?

Comments

Question 6: What other actions should we be taking to support promotion of mental wellbeing for individuals and within communities?

- It is important to ensure that there is effective support in the community and in an individual's home, as well as financial security and safe accommodation. Meaningful occupation in day centres and sheltered work settings can be beneficial for those without paid employment.
- Patients with schizophrenia who are discharged to an environment where there are high levels of criticism, hostility and over-involvement are three or four times more likely to relapse than those moving to an environment where these features are not present[v].
- It will be important to engender a more sophisticated understanding of mental wellbeing, and recovery that recognises the support required to help individuals achieve their own definition of recovery. This may not mean that they are symptom free, but that they are in a better position to build a meaningful life.
- A personalised and human rights approach to care can also improve wellbeing by focusing care and resource on what matters most to patients, and treating them with dignity and respect.

Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.

Question 7: What additional actions must we take to meet these challenges and improve access to CAMHS?

Comments

Question 8: What additional national support do NHS Boards need to support implementation of the HEAT target on access to specialist CAMHS?

Comments

Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.

Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?

- Self-care presents a particular challenge for patients with a mental illness such as schizophrenia or bipolar disorder, where their first contact with the health service may arise from a psychotic episode and where perceptions of reality and understanding of self are dramatically altered. At this time the patient may not have sufficient levels of self-awareness to enable them to self-care effectively and seek medical help when appropriate.

- Roche believes that further action is needed to support the implementation of the SIGN guidelines and monitor their impact on patient outcomes.

- In line with SIGN patients need swift access to high quality specialist services that adopt a shared care approach, stabilising symptoms and establishing a dialogue with the patient and carer that supports more effective management of their condition in future. This should include:

- Developing a supportive relationship with patients and carers
- Keeping clinical language to a minimum and providing written information at every stage of the process
- Timely, easy access to holistic assessment and treatment as soon as possible through all stages of care
- Assessment by a multidisciplinary team and close monitoring for other conditions
- Development of shared care plans and advance statements
- Regular review and assessment of symptoms and pharmacological treatment to support effective management of symptoms including negative symptoms, or depression and anxiety
- Appointment of a care co-ordinator
- Involvement of patients and families in self-help and support groups
- Family intervention programmes to enable a supportive family atmosphere and build an alliance between the patient and the family

Question 10: What approaches do we need to encourage people to seek help when they need to?

- In serious mental illness such as schizophrenia, it is necessary to stabilise symptoms of psychosis, and to manage the symptoms that can lead to social isolation and withdrawal. These negative symptoms can exacerbate co-morbidities and physical ill-health due to late presentation (or a failure to seek medical help altogether).

- People with mental health problems such as schizophrenia or bipolar disorder die on average 16–25 years sooner than the general population[vi]. They have higher rates of respiratory, cardiovascular and infectious disease and of obesity, abnormal lipid levels and diabetes[vii]. They are also less likely to benefit from mainstream screening and public health programmes.

- It is therefore important that clinicians seek to engage in a dialogue with the patient about the role of treatment in their health and wellbeing to support adherence.

- A culture of trust between patient and multidisciplinary team, family and carers can also help to establish a network of support conducive to the provision of timely care.

Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.

Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

- Roche is calling for appropriate workforce training to ensure that primary care professionals are in a position to identify mental ill health (including in instances where this may not be the primary reason for a GP visit) and to refer appropriately to secondary care providers.
- The Scottish Government should collect data on the proportion of patients presenting with first episode psychosis who go on to receive a diagnosis, full assessment and treatment for a specific condition such as schizophrenia and bipolar disorder. There is anecdotal evidence to suggest that clinicians may be reluctant to make a diagnosis because they fear that this will stigmatise patients as it creates a label which will stay with them for life. However, this can undermine the provision of appropriate treatment and care including both pharmacological and non-pharmacological interventions.

Outcome 5: Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

Question 12: What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

- As a first step, the evidence which underpins a range of interventions should be distilled and presented in an accessible way to support NHS Boards and key partners in re-designing services where appropriate.
- The consultation primarily addresses psychological therapies such as cognitive behavioural therapy (CBT) which can support patients with different types of mental illness, including depression, anxiety, schizophrenia and bipolar disorder. However it is equally important for NHS Boards to consider existing and emerging pharmacological treatments which have an important role to play within the overall treatment and care plan for each patient.
- It will be important for the SMC, SIGN and Health Improvement Scotland to issue new or updated guidance to reflect changes in the evidence base for existing interventions and emerging treatments. Models of best practice (eg in which a range of interventions are delivered as part of a comprehensive care plan) should shared between different boards.
- Roche recommends that health boards are required to collect data on the treatment and management of patients who access mental health services, and should publish information on patient outcomes at regular intervals. This would enable boards to benchmark their performance against that of their peers and encourage services to learn from high performers.
- Investment in evidence-based interventions and treatments for mental illness can

generate savings in other areas of public spending such as welfare, as a result of improved functioning. Attempts should be made to gather evidence about these benefits to underpin high-quality decision making.

Question 13: What support do NHS Boards and key partners need to put Integrated Care Pathways into practice?

- The integrated care pathways (ICPs) (Health Improvement Scotland) for mental health standards establish a framework for quality improvement through a series of process standards, generic care standards, condition-specific care standards and service improvement standards. The condition-specific care standards for schizophrenia should be reviewed over time to ensure that they address any developments in the evidence base and availability of new treatments. They could be further strengthened by an examination of the way that pharmacological and non-pharmacological treatments can complement each other. This will involve the delivery of a high quality assessment of a patient's positive and negative symptoms, as well as differentiation of other symptoms (eg of depression and anxiety), leading to the development of an integrated care and treatment plan.

- The process for service improvement (measuring how ICPs are implemented) could be strengthened by ensuring that data about adherence to the agreed ICP are published at a national level, rather than just being reported and evaluated at different levels within the health board. This would allow oversight of the extent to which the ICP programme is delivering for patients in Scotland as a whole and which boards in particular require further support. Where some boards have experienced success in implementing an effective ICP, the learnings should be shared with other boards through a range of channels (eg written guidance, workshops).

Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

Question 14: How do we continue to develop service user involvement in service design and delivery and in the care provided?

- The Scottish Government should also consider developing a patient experience survey for people with mental illness. This would help services to better understand:

  - How the provision of care could be better aligned to the interests and wishes of the patients
  - The factors which may undermine a patient's adherence to an agreed treatment regime and how these factors could be overcome
  - The patient's perceptions of the effectiveness of their treatment and care and the extent to which they feel the effects of their condition are being managed

- As part of the review of the ICP, the provision of education programmes for patients should be evaluated to ensure that they fulfil the following criteria:

  - Clear information on the patient's condition
  - Benefits and side effects of treatment
  - The role of treatment adherence in improving overall outcomes

Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?

- Boards should focus on the implementation of the SIGN guidelines and the Health Improvement Scotland standards of care as they apply to family intervention programmes and carer support.

- It will be important for boards to maintain their relationships with patient groups (eg the Scottish Mental Health Association and Support in Mind Scotland) to ensure that the design of services is based on a partnership between service users, families, carers and clinicians.

Question 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?

- Macmillan has developed a values standard to underpin the provision of cancer services. The standard aims to embed equality within the health service improvement agenda[viii]. This framework could be applied to other areas of healthcare including mental health. In schizophrenia this approach would give healthcare professionals the tools to better understand the needs and preferences of the patient, and work with them to provide care in a way that respects their dignity and their rights.

Question 17: How do we encourage implementation of the new Scottish Recovery Indicator (SRI)?

- The second Scottish Recovery Indicator was published in October 2011 to support a recovery based approach to mental health services. This presents an excellent opportunity to improve the outcomes of people living with different types of mental ill health. Recovery means different things to different people, and there is a difference between clinical recovery and personal recovery (which focuses less on being symptom-free and more being able to build a meaningful life and a sense of self-identity).

- Effective implementation should be based on the involvement of the voluntary sector as well as service users within local recovery networks. Because recovery is highly personal, service users with a range of conditions should be fully involved in each network. Service users should also be asked to report on the extent to which they feel supported in their recovery, which interventions and approaches that have worked well in their recovery, and these examples should be shared between networks.

Question 18: How can the Scottish Recovery Network develop its effectiveness to support embedding recovery approaches across different professional groups?

Comments

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Question 19: How do we support families and carers to participate meaningfully in care and treatment?

- Please see question 15

Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?

Comments

Outcome 8: The balance of community and inpatient services is appropriate to meet the needs of the population safely, efficiently and with good outcomes.

Question 21: How can we capitalise on the knowledge and experience developed in those areas that have redesigned services to build up a national picture of what works to deliver better outcomes?

- It is important that healthcare professionals find the right balance right between safety and risk management and a human rights based approach to care, which allows people to be cared for in the least restrictive environment possible. It is important that health boards invest in the skills of the multidisciplinary team to support effective management at home and in community settings wherever possible. The environment of secure wards should also be a priority for improvement.

Outcome 9: The reach of mental health services is improved to give better access to minority and high risk groups and those who might not otherwise access services.

Question 22: How do we ensure that information is used to monitor who is using services and to improve the accessibility of services?

Comments

Question 23: How do we disseminate learning about what is important to make services accessible?

Comments

Question 24: In addition to services for older people, developmental disorders and trauma, are there other significant gaps in service provision?

Comments

Outcome 10: Mental health services work well with other services such as learning disability and substance misuse and are integrated in other settings such as prisons, care homes and general medical settings.

Question 25: In addition to the work already in place to support the National Dementia Demonstrator sites and Learning Disability CAMHS, what else do you think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

Comments

Question 26: In addition to the proposed work in acute hospitals around people with dementia and the work identified above with female prisoners, are there any other actions that you think should be national priorities over the next 4 years to meet the challenge of providing an integrated approach to mental health service delivery?

Comments

Outcome 11: The health and social care workforce has the skills and knowledge to undertake its duties effectively and displays appropriate attitudes and behaviours in their work with service users and carers.

Question 27: How do we support implementation of *Promoting Excellence* across all health and social care settings?

Comments

Question 28: In addition to developing a survey to support NHS Boards' workforce planning around the psychological therapies HEAT target – are there any other surveys that would be helpful at a national level?

- Roche would welcome the development of a survey to evaluate the extent to which staff require additional skills or support to deliver the ICP for mental health standards and the extent to which they have the skills and capacity required to support patients with serious mental ill health.

- The Scottish Government should also consider developing a patient experience survey for people with mental illness (see question 14 above).

Question 29: What are the other priorities for workforce development and planning over the next 4 years? What is needed to support this?

- Key priorities for workforce development and planning over the next four years should be to:

- Maintain investment in the skills and capacity of the MDT (including psychiatric nurses) to ensure that there is sufficient support within the community/at home as well as within acute hospital settings
- Deliver the right balance right between safeguarding individuals and others, achieving a values based approach to care, and nurturing shared decision making
- Ensure that the workforce has the right skills to manage different types of mental ill health
- Upskill the workforce to ensure they are in a position to deliver high quality assessment, treatment and care – taking on board emerging evidence to support new interventions and treatments

Question 30: How do we ensure that we have sustainable training capacity to deliver better access to psychological therapies?

Comments

Outcome 12: We know how well the mental health system is functioning on the basis of national and local data on capacity, activity, outputs and outcomes.

Question 31: In addition to the current work to further develop national benchmarking resources, is there anything else we should be doing to enable us to meet this challenge.

- The national benchmarking project for mental health was last conducted in 2010 (published May 2011). It should be extended to incorporate the following data:

- Incidence, epidemiology, burden of disease
- Service delivery (eg number of clinicians, level of expenditure, number of hospital beds, prescribing rates, waiting times, length of stay, use of compulsory treatment orders, safety)
- Key outcomes achieved – these could be based on proxy outcome indicators where data is not yet available (eg patient experience, accurate diagnosis achieved, recovery rates, symptom management, active treatment rates – psychological and pharmacological, hospital re-admissions, work participation – paid or unpaid, attendance at day-care centres, training or education, management of co-morbidities, premature death due to physical ill-health, suicide rates)

- It is acknowledged that not all this data is routinely collected at present but that some of it could be initiated through existing processes, such as the ICP.

Question 32: What would support services locally in their work to embed clinical outcomes reporting as a routine aspect of care delivery?

- It will be necessary to establish a clear and routine reporting framework, and to integrate reporting where appropriate to minimise the burden on the NHS (eg ICP and benchmarking projects).

- Services should be encouraged to adopt an outcomes based approach to service delivery through a focus on recovery, a value based approach to care, and improving patient experience.

Outcome 13: The process of improvement is supported across all health and social care settings in the knowledge that change is complex and challenging and requires leadership, expertise and investment.

Question 33: Is there any other action that should be prioritised for attention in the next 4 years that would support services to meet this challenge?

- The Scottish Government should review the performance of services as part of an annual update of the Mental Health Strategy.

- This should incorporate the publication of comprehensive data (building on the national benchmarking project for mental health) by health board (see qu 31).

- The annual update/audit should identify examples of good practice and re-evaluate priorities where necessary.

- Where boards are underperforming, guidance should be developed to help them drive improvements in primary, secondary and tertiary services, as well identifying how redesign of the pathway as a whole could support improved outcomes and greater productivity.

- Guidance should be shared through more interactive channels such as workshops to identify how to improve outcomes and experiences of patients, whilst delivering efficiency across a range of different care pathways (eg bipolar, depression, schizophrenia, dementia).

Question 34: What specifically needs to happen nationally and locally to ensure we effectively integrate the range of improvement work in mental health?

- Roche recommends that the Scottish Government introduces national indicators to support integrated working and local improvement – these should be shared across different providers (health and social care).
- The annual update report (see question 33) could be launched at a national conference to bring together key stakeholders to agree priorities for the coming year.

Outcome 14: The legal framework promotes and supports a rights based model in respect of the treatment, care and protection of individuals with mental illness, learning disability and personality disorders.

Question 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?

- Workforce training should translate the principles of legislation into practice with examples of how the legal framework is applied in appropriate settings.
- Health boards should look to examples of good practice in this area – such as the Macmillan values standard[ix].

References

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