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Submission of: THE ROYAL COLLEGE OF PSYCHIATRISTS

Submission to: The Schizophrenia Commission

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

We are pleased to contribute written evidence to the Schizophrenia Commission. This evidence is provided by the General and Community, Rehabilitation and Social, Old Age and Academic Psychiatry Faculties of the Royal College of Psychiatrists and by the South West Division of the College.

This submission was approved by: Dr Laurence Mynors-Wallis, Registrar.

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1. General Comments

The Royal College of Psychiatrists welcomes and supports the work of the Commission in exploring the factors affecting all aspects of Schizophrenia.

1.1 Leadership for Schizophrenia

There is a balance to be struck when discussing schizophrenia between recognising that it can be a devastating illness with a long-term adverse impact on patients and carers, and the fact that there is a range of interventions that bring about real benefit and allow patients to lead rewarding and fulfilling lives. When considering services for patients with schizophrenia they must be adequately funded, patient-centred and have a focus on improved quality of life and social recovery, not only symptomatic improvement. Factors that enable this include having local care pathways that link primary care and early intervention with specialist rehabilitation for those at the more severe end of spectrum. Collaborative partnerships between commissioners and providers will be important for delivering a whole-system care pathway.

1.2 Late-life onset of schizophrenia

There are problems with late-life onset schizophrenia. Twenty per cent of all people who develop psychotic symptoms do so after their 85th birthday and the prevalence of late life schizophrenia is 2.4% at the age of 95. Thus, as the absolute number of people over 85 grows, the number of those with late-life onset schizophrenia is likely to become more noticeable. Particular issues include:

- The lack of a clear societal boundary between ‘eccentric’ and ‘psychotic’.
- People in this group having frequently managed to alienate themselves from social networks.
- People in this group often having a history of poor and/or unsatisfactory engagement with primary care and other health and social services,
consequently the prodromal period is among the longest of any mental illness.

- Cognitive impairment is not infrequent by the time of presentation.
- Early intervention services are absent for older people and there are often major environmental problems as a consequence of extended periods of social withdrawal.

As yet, high-quality multidisciplinary involvement with people with late-life onset schizophrenia is uncommon, and drug treatment rarely produces symptom resolution. As the number of people in this group is currently relatively small, there is an argument for the development of regional or sub-regional specialist services rather than leaving their management to individual sector teams. Further detail, about the issues for older people are included in our responses to the Commission’s specific consultation questions in section 3, below.

2. Issues for and from research

We see the following as key issues for and from research:

- Assessment of unmet need
- Improved inpatient services
- Need for effective parallel services of relevance to patients with schizophrenia, for example dual diagnosis and physical health
- Stigma, psychiatric leadership and clinical services
- More clinical academic input into and critical governance of NICE
- The need for more research - from basic neuroscience, to service delivery, to bolstering clinical academic careers
- The value of medication
- Stigma, Clinical Academic Leadership and the future of psychiatry.
2.1 Assessment of unmet need
There is a need for proper research-informed commissioning, for example into how we establish the extent of unmet need in the community, and fund services to meet this.

Insight is often lacking in such patients, and lack of engagement is a major problem. More research is needed to address these interactions.

Because of a shortage of beds, excessively high thresholds are being applied to admit patients who need urgent care, including those who need to be sectioned under the Mental Health Act. As a result many very ill patients remain untreated in the community, and invisible to funding.

2.2 Improved inpatient services

*Lack of beds*: the relative success of pharmacological treatments and community-based care has led to a significant and lasting reduction in hospital beds. Many surveys have identified failings in inpatient care but equally there are wards demonstrating good practice. Research is needed to identify the place of inpatient care not as an intervention of last resort but of value when needed. The RCPsych, through the Joint Commissioning Panel for Mental Health, is producing guidance for commissioners as to best practice in this area.

Too often, research studies have used bed stay as a marker either of the failure of treatment or the success of alternatives. Often, trial designs that support non-pharmacological interventions are less stringent than those which would pass for clinical trials for medicines. For example, the pragmatic trial design systematically favours a newer intervention, where there is no proper control for enthusiasm, novelty or the morale of teams with a mission to prove that their approach is superior to established approaches. The literature is filled with such trials which have often led to major changes in delivery of care without being given balanced consideration.
2.3 Need for effective parallel services of relevance to patients with schizophrenia
One third of patients with psychosis will have addiction problems. Many addiction services discharge patients who do not turn up to clinics, and home patients with psychosis get a poor service. This is a high-risk group, and individuals often need more intensive input, but more often than not receive less input than less complex cases. Addiction Services find significant difficulties because re-tendering processes have resulted in many being ‘outsourced’ to cheaper, non-psychiatry teams. Here is a lack of psychiatrist care for the most ill patients with psychosis, addiction problems and physical health problems. If this continues there will be a severe negative impact on schizophrenia services and patients. Addiction services need to provide an effective service parallel to that of community psychiatric teams. Insight is often lacking in such patients, and lack of engagement is a major problem. More research is needed to address these interactions.

2.4 Stigma, psychiatric leadership and clinical services
The value of medical leadership for individual patients, teams and services needs to be recognised.

It is to be hoped that with GPs in charge of commissioning there will be a more clinically informed commissioning process. When GPs refer patients they generally want their patients to be assessed thoroughly by psychiatrists, who appropriately delegate tasks to other team members. There are currently too many links in the chain from referral to assessment, which delays treatment. Patients also want to see a psychiatrist.

2.5 More clinical academic input into and critical governance of NICE
Great care needs to be taken of how NICE guidelines are interpreted. Sometimes it is the inclusion criteria which make the difference to whether a
treatment is recommended or not. A blind acceptance of guidelines as ‘fact’ needs to be resisted.

There is an ever-pressing need to generate the research evidence that may or may not be included in meta-analyses.

2.6 Need for more research - from basic neuroscience, to service delivery, to bolstering clinical academic careers
We need more work into how genes, neuro-imaging findings and other markers of the phenotype help provide the rationale for and predict treatment responses across the whole spectrum of psychopathology in schizophrenia, as well as its functional effects.

Gene-environment interactions are increasingly recognised as central to understanding schizophrenia. It is not all about either social or biological; psychological or psychiatric. A focus on different domains or specialties that traditionally specialise in particular approaches sometimes leads to a friction which handicaps progress. Whilst pharmacological treatments are often considered to be beset with side-effects, too often there has been an antipathy to these, without due consideration of the great benefits they provide. There has also too often been an antipathy to the pharmaceutical industry and an unbalanced distrust of it. This is not equally applied to non-medical treatments, where proponents may stand to gain financially or in reputation.

2.7 The value of medication
The Commission needs to recognise the real value of medication for improving the lives of patients with schizophrenia. Disinvestment by pharmaceutical companies in future developments for anti-psychotics is a real concern for patients, their carers and their doctors. Much is said about stigma in psychiatry of those with mental illness. It is important that the true impact of schizophrenia on patients and families is not hidden by avoiding the terms ‘illness’ and ‘schizophrenia’.
2.8 Stigma, clinical academic leadership and the future of psychiatry

The best strategy to dispel stigma is: research into causes and treatments and disseminating those success stories to others to give justifiable therapeutic optimism to patients and the general public. In these ways we can also tackle recruitment into psychiatry for the next generation. In our view, a research strategy that includes engendering interest in future clinical academic research should be integral to any strategy for schizophrenia.

3. Responses to Commission Consultation Questions

The comments below from individual Faculties / services supplement those we have made above.

Q1. What is your connection to mental health and specifically care and support for people with schizophrenia or psychosis?

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in the care and management of people with mental illness.

Q2. In your organisation or group's experience, what are the main impacts of living with schizophrenia or psychosis that you are trying to address through your own work?

- Distress caused by symptoms, both first-rank diagnostic importance and associated anxiety/depression
- Impairment of functioning – every day (poor sleep, etc) and social / occupational factors
- Challenging behaviour arising as a result of the symptoms
- Management of risk to self or others
• Helping patients manage early presentation or relapses so that they do not require admission.

We are trying to improve the recognition of schizophrenia in older people where it is often misdiagnosed as either dementia or “eccentricity”. This creates problems for older people with schizophrenia in accessing services for both physical and mental health care. We also encourage research into new treatments.

Q3. In your organisation or group’s experience, what are the main impacts of living with schizophrenia or psychosis from the perspective of a family member providing support that you try to address through your work?

• Advice on how to respond to symptoms and associated distress and behaviour
• Education about illness in general
• Relapse signature and alarm bell strategy work
• Intense and unpredictable stress when a family member is unwell and a chronic tension/ burden when they are not.

Older people with schizophrenia often live on their own or in care homes. Where they have family they are frequently alienated from their children because of their perceived behaviour or because of long periods of contact with mental health services if their illness first became apparent when young.

Q4. In your organisation or group's experience, what is the impact of schizophrenia or psychosis on communities and wider society?

They are variable. They can be devastating (suicide, violence). There is often grief over the loss of potential and considerable anxiety about how to help.
There are often difficulties with the level of support available to carers. There is also a massive impact on physical health.

Individuals with schizophrenia or psychosis are expensive to care for and the illness is stigmatised.

Older people with schizophrenia are virtually ignored by society. A high proportion of people with a long duration of schizophrenia reside in care homes because community facilities are so poor and are rarely focused on their needs. When schizophrenia develops in old age the person is more likely to be living alone than is the case with other forms of illness such as depression or dementia.

Q5. In your group or organisation’s experience, what have been the successes, if any, in the provision of care and support for people with schizophrenia or psychosis in terms of treatments?

Antipsychotics are helpful, but rarely completely eradicate the symptoms. Psychological treatments are helpful but hard to get hold of.

Crisis home treatment teams helping unwell patients stay in the community. The brief periods [maximum of two weeks] of supervised medication seem to be very effective.

There are very few studies which evaluate the effect of antipsychotic treatment on older people with schizophrenia. There are difficulties using Clozapine because of the co-morbid problems many older people have, and older people with schizophrenia do not tend to seek treatment. Psychological therapy provision is grossly lacking for most old people and there is no exception for those with schizophrenia. Family therapy for older people with schizophrenia is virtually unheard of. Much work needs to be done to promote the identification of older people with schizophrenia in the community and to
encourage them to access services so that the limited treatments available become more beneficial to them.

Q6. In your group or organisation’s experience, what have been the successes, if any, in the provision of care and support for people with schizophrenia or psychosis in terms of service provision?

In addition to crisis home intervention teams, Day Hospitals which provide therapeutic interventions and socialisation / normalisation.

Q7. In your group or organisation’s experience, what have been the successes, if any, in the provision of care and support for people with schizophrenia or psychosis in terms of workforce development and staffing?

As a reflection of the above, ensuring age-appropriate care for older people with schizophrenia is difficult. Many services are adopting an ‘age-blind’ approach, where service personnel do not have expertise in dealing with the needs of older people as compared to those of the younger people they generally manage. While there are some examples of community-based services for older people with schizophrenia, these are not common.

Q8. In your group or organisation’s experience, what have been the successes, if any, in the provision of care and support for people with schizophrenia or psychosis in terms of approaches and models for understanding mental illness?

The usual model is the Stress/Vulnerability model – more recently embedded within a framework of Recovery.

The development of a behavioural activation as a consistent approach.
Comments about the difficulty of older people with schizophrenia accessing medical services are equally pertinent to social and third sector care. However, members of our organisation have been instrumental in improving the identification and classification of schizophrenia in older people, making identification and management easy.

**Q9. In your group or organisation’s experience, what have been the successes, if any, in the provision of care and support for people with schizophrenia or psychosis in terms of the reactions of wider society?**

As stated above, older people with schizophrenia are almost ignored by society and there is a major danger of assault. Self-neglect is by far the most common “non-medical” problem, as society is reluctant to interfere with what they see as the perceived choice of the individual.

**Q10. In your organisation’s experience, what has been the single most important development or innovation for improving outcomes for people with schizophrenia or psychosis in the last few years?**

The use of clozapine and the recovery model have been important, as has the beginning of an anti-stigma campaign.

With respect to older people, only improved classification would qualify. However, the ability of good quality rehabilitation services to maintain contact with people with schizophrenia who age has almost certainly led to those individuals having a better experience of contact with society than was the case previously.
Q11. What research and scientific developments (if any) are you most interested in for progressing care and treatment for people with schizophrenia or psychosis?

Improvements in both psychological and pharmacological interventions would be of great interest, including for older people. We need better medication, as a third of patients do not respond well to treatment.

There is a need for more understanding of basic disease processes, the link with substance misuse and links with physical morbidity.

Q12. In your group or organisation’s experience, what, if any, are the current challenges for delivering care and support to people with schizophrenia or psychosis in terms of treatments?

Drugs are only partially efficacious - psychological treatments are also partially efficacious and not widely available. In addition, resources are scarce and the current focus is not on psychoses.

Q13. In your group or organisation’s experience, what, if any, are the current challenges for delivering care and support to people with schizophrenia or psychosis in terms of service provision?

- Psychology services/interventions are patchy, especially to inpatient units.
- There is often a long wait for rehabilitation for the more disabled.
- The provision of appropriate housing and occupation are also highly variable.
- Under-resourcing is a problem and is likely to get worse.

There are major issues for people with schizophrenia as they approach their 65th birthday. Services for “working age” adults are usually comprehensive,
and the care programme approach almost uniform. In many cases services disappear on or around the person’s 65th birthday. Day opportunities and personalised care homes are grossly lacking for this age group for dealing with schizophrenia or psychosis.

**Q14. In your group or organisation’s experience, what, if any, are the current challenges for delivering care and support to people with schizophrenia or psychosis in terms of workforce development and staffing?**

There is no clear strategy to develop a workforce capacity able to deal with the demands created by people with schizophrenia in particular.

**Q15. In your group or organisation’s experience, what, if any, are the current challenges for delivering care and support to people with schizophrenia or psychosis in terms of approaches and models to understanding mental illness?**

We have a workable model – but there are challenges linked to the issues set out in response to Qs 13 and 14 above.

**Q16. In your group or organisation’s experience, what, if any, are the current challenges for delivering care and support to people with schizophrenia or psychosis in terms of reactions in wider society?**

Ignorance is a problem, with appalling and stigmatising media attitudes. There is also an issue of how mental illness is represented in the media, especially in fictional thrillers/murder mysteries.
Q17. In your group or organisation’s experience, what is the single most difficult challenge (besides money!) for improving outcomes for people with schizophrenia or psychosis?

Lack of effective treatment for cognitive problems.

Persuading people of the benefits for older people of re-integrating with a social network.

Q18. What are the specific challenges faced by your organisation, if any, in supporting recovery with people with schizophrenia or psychosis and their families?

Money and staff are challenges.

More attention needs to be given to quality, not only to quantity. Measures focus on ‘completed episodes’, which encourages brief care of a group requiring continuity of care.

Another issue is the inability of services to provide sufficient comprehensive support to allow an older person to utilise the vast proportion of their time effectively. Effective utilisation of time is perhaps the single best indicator of the level of recovery in an older person.

Q19. What are you most proud of as a group or organisation in terms of improving outcomes for people with schizophrenia or psychosis, and their families?

Embedding the recovery model.
Increasing the recognition that older people with schizophrenia are not “eccentric” and that they are entitled to good quality physical and mental medical care.
Q20. How have NICE schizophrenia guidelines made a difference to how you deliver care and support?

They provide the basic benchmark. However, these are focused on younger people and make little difference to older adults.

Q21. Are there any other guidelines or frameworks that your organisation finds helpful?

The Maudsley Guidance.

Q22. In your opinion what does the NHS (primary and secondary care services) need to change in order to improve how people with schizophrenia or psychosis are supported?

In addition to our comments in Section 2, above, being more assertive in contact and follow-up would be an improvement. Carefully considered commissioning is also very important.

Q23. Please use the space below to tell us about your hopes for the future for people with schizophrenia.

Services should be integrated and consistent for the patient. They need to be developed with patients/carers, but at present their involvement is peripheral.

In addition to the above, the College’s Rehabilitation and Social Psychiatry Faculty would like to highlight the following information from the Faculty section of the College website: http://www.rcpsych.ac.uk/specialties/faculties/rehabilitationandsocial.aspx
• Presentation: An overview of rehabilitation services in Scotland
• **FR/RS/03:** Rehabilitation services in the UK and Ireland: current status and future need

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