Croydon Joint Strategic Needs Assessment 2012/13

Key-Topic: Schizophrenia

APPENDICES

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The data in this chapter was the most recent published data as at (insert date). Readers should note that more up-to-date data may have been published subsequently, and are advised to refer to the source shown under figures or listed in the appendices for the chapter for the latest information.

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1 Appendix 1 - JSNA implementation group members

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2 Appendix 2: Schizophrenia: condition, causes and impact

Schizophrenia is a major psychiatric disorder, or cluster of disorders, characterised by psychotic symptoms that alter a person's perception, thoughts, affect, and behaviour. The symptoms are usually divided into positive symptoms, including hallucinations and delusions, and negative symptoms, such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect. Nevertheless, people who develop psychosis and schizophrenia will have their own unique combination of symptoms and experiences; the exact pattern will be influenced by their particular circumstances (eg life experiences, ethnicity) and will require flexibility in service response. Schizophrenia can have a major impact on people's personal, social and occupational lives due not only to recurrent episodes/symptoms but also to the side effects of treatment, to social problems, isolation, poverty, and homelessness and the associated prejudice, stigma and social exclusion.[1, 2]

The usefulness of schizophrenia as a diagnosis has been questioned in that: it covers a broad range of symptoms; it has blurred borders with normality, bipolar disorder and depression; it engenders stigma and discrimination. In fact the term pyschotic illness may sometimes be used as the overarching category to include schizophrenia, bipolar disorder and other psychoses. However, according to the Royal College of Psychiatrists, there is no other agreed term for the pattern of symptoms and behaviours that schizophrenia describes.[3] The up-dated United States Diagnostic and Statistical Manual of Mental Disorders (DSM V) due to be published in 2013 recommends keeping the diagnosis. And it is likely that the International Classification of Disease 11th edition, the other main classification manual, will do the same.[4]

[1]National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.
[2]National Institute for Health and Clinical Excellence*. Psychosis and schizophrenia in adults: treatment and management. Scope final version.* 2012. NICE.
[3]Royal College of Psychiatrists.Schizophrenia leaflet. http://www.rcpsych.ac.uk/expertadvice/problems/schizophrenia/schizophrenia.aspx
[4]The Schizophrenia Commission.*The Abandoned Illness.* Rethink Mental Illness, November 2012.

Approximately 1 in 100 people will develop schizophrenia in their life. It is more common in populations including: Black Caribbean and black African populations, migrants and their children, people who are homeless, unemployed, living in high density urban areas and people living in areas of high deprivation.[5]

2.1 Links between psychosis and schizophrenia

Psychosis is a disturbance in how people perceive and think about the world that is severe enough to distort perceptions of reality. The main symptoms are hallucinations, where a person hears, sees (and in some cases smells) things that are not really there, delusions where a person believes things that, when examined rationally, are untrue and disorganised thinking.

Psychosis is a symptom triggered by conditions that include not only schizophrenia, but also bipolar disorder, Parkinson's disease, misuse of drugs or alcohol and some other conditions.

An episode of psychosis may signal the start of the development of schizophrenia. However the general term "psychosis" is preferable at least in the early stages, because of the stigma generated by a diagnosis of schizophrenia and the possibility of other causes and diagnoses. [6]

2.2 Groups at increased risk of schizophrenia

Some groups are at higher risk of schizophrenia including:

- Those living in institutional settings
- People who are homeless
- Black Caribbean and Black African
- Prisoners and offenders
- Those who misuse substances

Institutional settings

Prevalence of psychotic disorder is consistently higher in specialised institutional setting such as judicial & custodial services, homeless shelters and residential homes than in the general population.

[5]National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.
[6] The Schizophrenia Commission.*The Abandoned Illness.* Rethink Mental Illness, November 2012

Homelessness

Homeless people in Western countries are substantially more likely to have alcohol and drug dependence than the age-matched general population in those countries, and the prevalences of psychotic illnesses and personality disorders are higher[7]An estimated 43% of clients in an average homelessness project in England are likely to have mental health needs, and 59% may have multiple needs.[8]

Black Caribbean and Black African

People of black Caribbean or African origin, both migrants and their descendants, have a significantly increased risk of schizophrenia. There is a raised rate of of schizophrenia in descendants from the Indian sub-continent, particularly for women. Evidence points to raised rates among people of mixed ethnicity, a possible marker of 'third-generation' descendants, and there is some evidence of a smaller but significant elevation of rates amongst non-British white migrant groups.[9] The elevated rates among migrant and minority ethnic groups may be associated with greater exposure to various forms of social adversity and difficult social contexts over the life course. On this basis, people from Asian backgrounds may have benefitted from the greater protective effects of familial and social supports, which are assumed to be stronger in Asian populations.[10]

Prisoners and offending.

Patients with schizophrenia have been shown to be at increased risk of criminality, especially violent crimes.

Of 10 million prisoners worldwide, about 400,000 individuals with psychosis are currently in custody. Rates of re-offending are high in al categories of prisoners. Individuals with a psychotic disorder including schizophrenia have a modestly higher risk of repeat offending compared to persons without any psychiatric disorder; women with psychotic disorders are at higher risk for repeat offending than women with other psychiatric disorders.[11]

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[7]Fazel S, Khosla V, Doll H, Geddes J (2008) The Prevalence of Mental Disorders among the Homeless in Western Countries: Systematic Review and Meta-Regression Analysis. *PLoS Med* 5(12): e225

[8]St Mungo's (2009). Down and Out? The final report of St Mungo's Call 4 Evidence: mental health and street homelessness. London.

[9]Kirkbride JB, Errazuriz A, Croudace TJ, Morgan C, Jackson D, Buydell J, Murray, RM, Jones PB (2012) incidence of schizophrenia and other psychoses in England, 1950-2009: a systematic review and meta-analyses. *PLoS ONE* 7 (3) e31660

[10] Morgan C, Charalambides M, Hutchinson G, Murray RM. (2010) *Schizophrenia Bulletin* 36 (4) 655-664

[11]Fazel S, Yu R (2011) Psychotic disorders and repeat offending; systematic review and meta-analysis *Schizophrenia Bulletin* 37 (4) 800-810

It has been found that there is a substantially increased risk of arson in patients with schizophrenia and other psychoses.[12] Elevated risks of violent behaviour are associated with schizophrenia, particularly with substance abuse co-morbidity; there are suggestions of significant impact of familial (genetic or early environment) associations[13]

Substance abuse

Co-occurring substance abuse[14] and comorbid alcohol use[15] have a substantial impact on the hospitalisation rates and the life expectancy of patients with dual diagnosis.

2.3 What is the course of the illness?

The first symptoms tend to start in young adulthood (75% of mental health disorders emerge prior to 25 years old[16]) usually at a time when people are trying to make the transition to independent living, but they can occur at any age. The problems of schizophrenia are usually preceded by a 'prodromal' period characterized by some deterioration in personal functioning such as memory and concentration problems, social withdrawal, unusual and uncharacteristic behaviour, disturbed communication and emotional expression, bizarre ideas and perceptual experiences, poor personal hygiene, reduced interest or motivation for day-to-day activities. This prodromal period is typically followed by an acute phase marked by positive symptoms. Following resolution of the acute phase, usually following some form of treatment, positive symptoms reduce or disappear for many, sometimes leaving a number of negative symptoms. This third phase, which can last for many years, is often interrupted by acute relapses, which may need additional interventions.[17] Around 45% of people with a diagnosis of schizophrenia recover after one or more episodes; about 20% have unremitting symptoms and disability; the remaining 35% show a mixed pattern of remission and

[12] Anwar S, Langstrom N, Grann M, Fazel S (2011) Is arson the crime most strongly associated with psychosis? – A national case-control study of arson risk in schizophrenia and other psychoses. *Schizophrenia Bulletin* 37 (3) 580-586

[13]Fazel S, Langstrom N, Hjern A, Grann M, Lichtenstein P (2109) Schizophrenia, substance abuse and violent crime *JAMA* 301 (19) 2016-2023

[14] Schmidt LM, Hesse M, Lykke J (2011) The impact of substance use disorders on the course of schizophrenia – a 15 year follow-up study: dual diagnosis *Schizophrenia Research* 130 (1) 228-33

[15] Jones RM, Lichtenstein P, Grann M, Langstrom N, Fazel S. Alcohol use disorders in schizophrenia: a national cohort study of 12,653 patients. *Journal of Clinical Psychiatry* 72 (6) 775-9

[16]IRIS initiative.*IRIS Guidelines Update*, September 2012.

[17]National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.

relapse.[18]

The prognosis, social functioning and response to treatment have all been found to be better in women than men. One explanation is that the later age of onset experienced by women allows better adjustment. Women have also been shown to need more risk factors (more familial risk and life events) to develop schizophrenia than men.[19]

2.4 What causes schizophrenia?

It is thought that schizophrenia and related psychoses result not from one single cause but from a range of interacting biological, psychological and social factors that determine someone's level of vulnerability. Some of the factors which increase a person's vulnerability to schizophrenia are genetic inheritance; brain injury at the time of birth; separation from a parent. Schizophrenia can then be triggered in those who are vulnerable by stressful life events and traumas: such as bereavement, job loss, end of a relationship; physical, sexual, emotional or racial abuse. Migrant groups and their children are 2-8 times more likely to develop psychosis.[20] Heavy use of amphetamines and cannabis has also been shown to increase risk. However epidemiological studies have not shown the increased incidence that would be expected if increased cannabis use were having an effect.[21]There is evidence that too much dopamine may be involved in the development of schizophrenia, although it is not clear how,nor whether everyone diagnosed with schizophrenia has too much dopamine. All the factors that increase the risk of psychosis impact on brain dopamine levels.[22] Antipsychotic drugs, which are generally used to treat schizophrenia, target the dopamine system. Research into other possible causes, including viruses, hormonal activity (particularly in

[18] Barbarato 1998 cited in: The abandoned Illness: A Report by the Schizophrenia Commission. November 2012.

[19] Ochoa S, Usall J, Cobo J, Labad X and Kulkarni J. Gender differences in schizophrenia and first-episode psychosis: A comprehensive literature review. *Schizophrenia Research and Treatment,* Vol 2012 (2012).

[20]HM Government/Department of Health.*No health without mental health: a cross-government mental health outcomes strategy for people of all ages*. February 2011. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

[21]Kirkbridge JB, Errazuriz A, Croudace TJ, Morgan C, Jackson D, McCrone P, Murray RM & Jones PB. *Systematic review of the incidence and prevalence of schizophrenia and other psychoses in England*. Conducted for the Department of Health Policy Reseach Programme, February 2011.University of Cambridge.

[22]Di Forti et al (2007) cited in The abandoned Illness: A Report by the Schizophrenia Commission. November 2012.

women), diet, allergic reaction or infection is ongoing.[23]

2.5 What is the impact?

Health.
Schizophrenia is associated with a higher risk of other mental health problems, poorer physical health, less healthy lifestyles and lower life expectancy. People with schizophrenia are more likely to have depression, anxiety, post-traumatic stress disorder, personality disorder, and substance misuse.[24] Physical health problems are also more common. People with schizophrenia are more likely to smoke, be obese, have diabetes and have had a stroke.[25] People with schizophrenia die 15-20 years earlier than other people,.[26] The reasons for this are complex, resulting from lifestyle factors, poorer access to healthcare, [27] side effects of medication and higher rates of suicide, accidental and violent death.[28]

Social
The first few years after onset can be particularly upsetting and chaotic, and there is a higher risk of suicide. Once an acute episode is over, there are often additional problems with social functioning resulting in social exclusion, difficulties in getting back to work or study and problems making new relationships. Such interruption in personal and social development can have lifelong effects and results in much of the disability experienced by people with chronic mental illness. The symptoms and behaviour associated with schizophrenia can also have a distressing impact on family and friends. The World Health Organisation has calculated that at a family level the burden and human suffering caused by psychosis was only exceeded by quadriplegia and

[23]Understanding schizophrenia.MIND web-site.Accessed 2.12.12. http://www.mind.org.uk/help/diagnoses_and_conditions/schizophrenia#causes
[24]National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.
[25]Report to the Disability Rights Commission. Health Inequalities experienced by people with schizophrenia and manic depression. Analysis of general practice data in England and Wales. Report prepared by: Professor Julia Hippisley-Cox Professor Mike Pringle Final version submitted: April 2005. Final version submitted: April 2005. Q Research.
[26] Chang C-K, Hayes RD, Perera G, Broadbent MTM, Fernandes AC, et al. (2011) Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. PLoS ONE 6(5): e19590. doi:10.1371/journal.pone.0019590
[27]LawrenceD and Kisely S. Inequalities in healthcare provision for people with severe mental illness.*J Psychopharmacol.* 2010 November; 24(4_supplement): 61–68.
[28] Thornicroft G (2011) Physical health disparities and mental illness: the scandal of premature mortality. British Journal of Psychiatry, 199: 441-442.

dementia.[29] In addition, the diagnosis of schizophrenia is still associated with considerable stigma, fear and limited public understanding.

Financial impact

Unlike physical illness, which increases steadily throughout life, morbidity (ill health) from mental illness disproportionately affects people of working age, particularly those aged 15-44 years. Hence mental ill health impacts heavily on the economy. The total annual societal cost of schizophrenia in England was estimated at £11.8 billion per year (2010/11 prices) equating to £60,000 per individual with schizophrenia.[30] There are further costs that fall within the public sector that include social security payments and forgone tax that total a further estimated £16,000 per individual per year with schizophrenia. People with schizophrenia use over 60% of the inpatient provision.[31]

[29]IRIS initiative.*IRIS Guidelines Update*, September 2012

[30] Andrew A, Knapp M, McCrone PR, Parsonage M, Trachtenberg M (2012) Effective interventions in schizophrenia: the economic case. Personal Social Services Research Unit, London School of Economics and Political Science, London, UK

[31]Knapp 1997 cited in National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.

3 Appendix 3 National policy, policy agendas and national guidance

3.1 National policies

A number of key policy documents have been published in recent years which influence how care for people with schizophrenia is provided:

In 1999, the *National service framework for mental health* focused on modernising standards and service models with the aim of improving quality and reducing unacceptable variations in health and social services.[32] The Mental Health Policy Implementation Guide specified new models of service for crisis resolution home treatment teams, assertive outreach teams and early intervention in psychosis teams in specialist mental health provision.[33]

In 2008, the Foresight report *Mental Capital and Wellbeing: Making the most of ourselves in the 21st century*[34] stressed the importance of mental capital and wellbeing for the healthy functioning of families, communities and society. It presented evidence about the factors that can enhance or deplete mental capital and wellbeing throughout life; how these are affected by government policy, key stakeholders, and the environment in which we live; and set out policy interventions for tackling the mental capital and wellbeing challenges throughout the life course. This increased the focus on the prevention of mental health problems and the promotion of wellbeing.

New Horizons: A shared vision for mental health[35] the labour government's mental health strategy, published in 2009, drew heavily on the Foresight report. It recognised mental health and wellbeing as a major social issue requiring action across all parts of Government, stating: "Good mental health is fundamental to the resilience of individuals, families, communities and businesses. It decides, in short, whether a society is flourishing or

[32]Department of Health.*National service framework for mental health - modern standards and service models.* 1999. Crown copyright http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006057

[33]Department of Health.*The Mental Health Policy Implementation guide.*

[34]Foresight Mental Capital and Wellbeing Project.*Making the most of ourselves in the 21st century Final Project report - Executive summary*.Government Office for Science.

[35]Department of Health.*New Horizons: a shared vision for mental health.* 2009. Crown copyright http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109705

floundering." It combined service improvement with partnership working to strengthen the mental health and well-being of the whole population.

The coalition Government published their strategy *No health without mental health: A cross government mental health strategy for all ages* in 2011.[36]The two themes which underpin this strategy are: mental health is everyone's business and more decisions should be taken locally based on need. It aims to mainstream mental health in England giving it parity with physical health and takes a life course approach, starting in pregnancy and continuing through to old age, to consider six key objectives:

1. More people will have good mental health
2. More people with mental health problems will recover
3. More people with mental health problems will have good physical health
4. More people will have a positive experience of care and support
5. Fewer people will suffer avoidable harm
6. Fewer people will experience stigma and discrimination

The recently published *No Health without Mental Health: Implementation Framework* considers how this strategic vision can be translated into reality; how progress can be measured and reported; what local organisations can do to implement the strategy; and what support will be provided at national level.[37]

All these policies impact on how care and treatment of people with, or at risk of developing, schizophrenia is provided now and in the future. Over the years policy thinking has broadened the focus from the more clinical aspects of care and treatment to the social, with the promotion of wellbeing, the prevention of mental illness, and recovery focused care assuming greater importance.

3.2 Key policy agendas

3.2.1 Promoting recovery

Recovery has gained impetus as a social movement over the last 10-15 years as a result of a perceived failure by services and wider society to adequately support social inclusion, and from studies demonstrating that many people

[36]HM Government/Department of Health.*No health without mental health: a cross-government mental health outcomes strategy for people of all ages*. February 2011. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

[37] Centre for Mental Health, Department of Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness, Turning Point. No health without mental health: Implementation framework. July 2012.

with mental illness can recover.[38] A distinction is made in the literature between clinical recovery, which comes from the expertise of mental health professionals (and relates to getting rid of symptoms, restoring social functioning, and getting back to normal) and personal recovery, which relates to the expertise of people who have experienced mental illness.[39] Personal recovery is defined as:

> *'a deeply personal, unique process of challenging ones attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.'*[40]

Some of the elements of recovery are having hope, a secure base (ie a home, income, freedom from violence, access to healthcare), a durable sense of self, supportive relationships, empowerment or inclusion, and coping strategies. From a service point of view, supporting personal recovery means moving away from a focus on treating illness towards promoting wellbeing.

3.2.2 Personalisation in mental health

Personalisation is a social care approach which according to the Department of Health should mean that: "every person who receives support, whether provided by statutory services or funded by themselves will have choice and control over the shape of that support in all care settings." Personalisation is often associated with Direct payments and Personal Budgets where service users can choose the services they receive. It requires services to be tailored to individual need and includes the provision of information and advice to families, investment in prevention services to reduce or delay the need for care, and the promotion of independence and self-reliance amongst individuals and communities.[41] Hence it supports the recovery oriented approach to service provision. Users have pointed out that it needs to take

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[38] Grove, B. *Factors influencing recovery from serious mental illness and enhancing participation in family, social and working life*. State of Science Review: SR-B9 for Government's Foresight Project, Mental Capital and Wellbeing. Government Office for Science.

[39] Slade M. *100 ways to support recovery: A guide for mental health professionals.* Rethink recovery series volume 1, 2009.

[40] Anthony WA. *Recovery from mental illness: the guiding vision of the mental health system in the 1990s*. Innovations and Research 1993; 2:17-24 cited in Slade M. 100 ways to support recovery: A guide for mental health professionals. Rethink recovery series volume 1, 2009.

[41] Community Care.*Expert guide to personalization*.Accessed 24th October 2012.http://www.communitycare.co.uk/Articles/25/07/2012/109083/personalisation.htm

account of the fact that people's condition fluctuates and support is still needed when they are better to keep them well.[42]The Community Care Expert Gide to Personalisation states that the key test of personalisation's success is the extent to which it improves the lives of service users and carers.

The Social Care white paper has introduced a number of measures to support the introduction of personalisation: a requirement for all users of community-based, council funded support to be on personal budgets by April 2013; testing the extension of direct payments to residential care; the introduction of a duty on councils to commission services that prevent, reduce or delay the need for care, backed up by a national care and support evidence library, and a pilot to test 'social impact bonds' (a contract where a public sector commissioner pays for improvement in social outcomes for a defined population[43]). Personalisation encourages commissioners to move away from block contracts (an amount of activity for a particular price) to directly purchasing individual packages of care.[44]

3.2.3 Payment by Results (PbR)

A move away from block contracting is also occurring in NHS provision and will impact on how services are commissioned. PbR was to be introduced into mental health services to replace block contracting from 2012/13. It is a way of paying NHS hospital and community health services for the quantity of work done, based on the number and type of cases treated. The currencies are associated with the individual service users, their interactions with mental health services and the packages of care they receive.[45] A mental health clustering tool is to be used to allocate each patient to a classification system based on the severity of problems experienced recently (past two weeks) and historically (occur in an episodic or unpredictable way). This tool incorporates items from the Health of the Nationals Outcome Scales (HoNOS) and the Summary Assessments of Risk and Need (SARN). Local prices will initially be based on the cost of care clusters, but in the future the amount paid may be determined by a national tariff (a fixed non-negotiable price).[46] It is recognised that Mental Health PbR needs to support the recovery focus of *No Health without Mental Health* and theDepartment of Health are in the process of

[42]MIND.*Personalisation in mental health:Creating a vision.*Views of personalization, from people who use mental health services.MIND 2009.
[43]Social Finance.Social impact bonds. http://www.socialfinance.org.uk/work/sibs
[44].Bennett A, Appleton S and Jackson C. Practical mental health commissioning: A framework for local authority and NHS commissioners of mental health and wellbeing services. Volume one: setting the scene. Joint Commissioning Panel for Mental Health. March 2011.
[45]The Sainsbury Centre for Mental Health.Policy paper 4.*Payment by Results: what does it mean for mental health?* December 2004.
[46]Department of Health Payment by Results Team.*Mental Health Clustering Booklet 2012-13.*

developing outcome indicators that align with the three outcomes frameworks.

3.2.4 Focusing on outcomes

The focus on outcomes has resulted in the development of a number of outcomes frameworks, which will help to push the current policy agenda forward. The Public Health Outcomes Framework,[47] the NHS Outcomes Framework[48] and the Adult Social Care Outcomes Framework[49]have been designed to interlink so they work together towards shared outcomes and goals.[50] Some of the outcome measures and the means of data collection are still in development. Improvements in care for people with schizophrenia will lead to improvement in many indicators and outcomes across the three frameworks that include:

- Reducing premature death in people with severe mental illness
- Enhancing quality of life for people with mental illness
- Improving experience of healthcare for people with mental illness
- People in prison who have a mental illness or significant mental illness
- Proportion of adults in contact with secondary mental health services in paid employment
- Proportion of adults in contact with secondary mental health service living independently, with or without support

3.2.5 Preventing Relapse

Relapse, whereby people experience a crisis that may lead to inpatient admission has a negative effect on the individual's health and wellbeing and is costly. People with schizophrenia use over 60% of the inpatient provision.[51] Inpatient time for people with schizophrenia accounts for roughly 38% of the

[47]Department of Health.*Healthy lives, healthy people: Improving outcomes and supporting transparency*. January 2012.
[48]Department of Health.*The NHS Outcomes framework 2012/13*. December 2011.
[49]Department of Health.The *Adult Social Care Outcomes Framework 2013/14*. November 2012.
[50]Bennett A, Appleton S and Jackson C.*A framework for Local Authority and NHS commissioners of mental health and wellbeing services. Volume 1: Setting the scene*. Joint Commissioning Panel for Mental Health, 2011.
[51]Knapp 1997 cited in National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.*Updated edition 2009.National Institute for Health and Clinical Excellence.

total health, social care and institutional costs.[52] Hence approaches that reduce hospitalisation and relapse and potentially enable people with schizophrenia to return to active employment could significantly reduce the societal burden of schizophrenia.

A number of factors have been found to increase the risk of hospital admission: history of early onset; recent inpatient admission; first admission shorter than two weeks (compared to 4 weeks); discharged due to bed crisis; not in remission at discharge; less likely to be taking a second generation antipsychotic at discharge; severe positive symptoms; poor social functioning; lack of insight or denial of illness; high global illness severity; comorbid substance misuse disorders; poor interpersonal relationships; poor adherence to treatment. Clozapine has been shown to delay hospitalisation in patients with treatment resistance if started in the community or successfully discharged from hospital after index admission.[53], [54], [55], [56], [57], [58]

A recent study at South London and the Maudsley (SLaM) found that treatment non-adherence was implicated in 76% of relapses (in more than 50% cases it was a definite cause of relapse). Only a third of the study population were receiving psychotropic medications on admission, which always included at least one antipsychotic. Weiden and colleagues estimated that the rate of outpatient non-adherence to maintenance antipsychotic treatment was 50% within one year of discharge and 75% within two years of

[52] Andrew A, Knapp M, McCrone PR, Parsonage M, Trachtenberg M (2012) Effective interventions in schizophrenia: the economic case. Personal Social Services Research Unit, London School of Economics and Political Science, London, UK

[53] Olfson M, Ascher-Svanum H, Faries DE, Marcus SC. Predicting psychiatric hospital admission among adults with schizophrenia. *Psychiart Serv*, 2011 Oct: 62 (10): 1138-45.

[54] Munro J, Osborne S, Dearden L, Pascoe K, Gauthier A, Price M. Hospital treatment and management in relapse of schizophrenia in the UK: associated costs. *The Psychiatrist* (2011) 35: 95-100.

[55] Schennach R, Obermeier M, Meyer S, Jagar M, Schmauss m, Laux G, Pfeiffer H, Naber D, Schmidt LG, Gaebel W, Klosterkotter J, Heuser I, Maier W, Lemke MR, Ruther E, Klingberg S, Gastpar M, Seemuller F, Moller HJ, Riedel M. Predictors of relapse in the year after hospital discharge among patients with schizophrenia. *Psychiatric Services*, January 2012, vol./is.63/1(87-90).

[56] Niehaus DJ, Koen L, Galal U, Dhansay K, Oosthuizen PP, Emsley RA, Jordaan E. Crisis discharges and readmission in acute psychiatric male inpatients. *BMC psychiatry*, 2008, vol/is. 8/(44).

[57] Schennach R, Obermeier M, Meyer S, Jagar M, Schmauss m, Laux G, Pfeiffer H, Naber D, Schmidt LG, Gaebel W, Klosterkotter J, Heuser I, Maier W, Lemke MR, Ruther E, Klingberg S, Gastpar M, Seemuller F, Moller HJ, Riedel M. Predictors of relapse in the year aafter hospital discharge among patients with schizophrenia. Psychiatric Services, January 2012, vol./is.63/1(87-90).

[58]Boden r, Brandt L, Kieler H, Reutfors J.Early non-adherence to medication and other risk factors for rehospitalisation in schizohrenia and schizoaffective disorder.*Schizophrenia Research*, December 2011, vo./is. 133/1-3(36-41).

discharge.[59]The risk of relapse after a first episode of psychosis is reported to be five times higher in those who discontinue antipsychotic treatment.[60]

Vermeire and colleagues point out however that in much of the research on adherence to treatment the patient perspective is missing.[61] It has been shown that adherence is influenced not only by person-related factors (such as impaired insight into the need for the medication) but also by the person's relationship with the physician and factors relating to the medication itself. The relative contribution of each could not be ascertained in the SLaM study.[62]

Preventing hospital admission is important, as it is costly. Money not spent on hospital admission could be reinvested elsewhere in the system. The SLaM study estimated that the mean cost of relapse, at 2006 prices, was almost £26,000 (ranging from £1,270 - £120,000); 97% were hospital costs and 3% drug costs. This is also an underestimate in that the cost of after-care is not included; treatment costs for people in the first six months after relapse have been shown to be more than four times higher than in those who did not.[63]

Risk of relapse has been estimated at 3.5% per month and approximately 40% experience relapse within a year of admission. Seventy percent of the admissions in the study were under the Mental Health Act a key driver of cost, although the main driver was length of stay. A study conducted in Greece found that LOS was increased in those with physical comorbidities.[64]

Hence efforts to reduce relapse can decrease healthcare costs incurred by people with schizophrenia, improve their outcomes in health and social inclusion and reduce the societal burden.

[59] WeidenPJ, Zygmunt A. Medication noncompliance in schizophrenia. Part 1: Assessment. *J Prac Psych Behav Health* 1997; 3: 106-10

[60] Robinson D, Woerner MG, Alvir JM, Bilder R, Goldman R, Geisler S, et al. Predictors of relapse following response froma first episode of schizophrenia or schizoaffective disorder. *Arch Gen Psychiatry* 1999; 56:241-7.

[61] Vermeire E, Hearnshaw H, Van Royen P, Denekens J. Patient adherence to treatment: three decades of research. A comprehensive review.*J Clin Pharm Ther*. 2001 Octo;26(5):331-42.

[62]Munro J, Osborne S, Dearden L, Pascoe K, Gauthier A, Price M. Hospital treatment and management in relapse of schizophrenia in the UK: associated costs. *The Psychiatrist* (2011) 35: 95-100.

[63] Almond S, Knapp M, Francois C, Toumi M, Brugha T. Relapse in schizophrenia: costs, clinical outcomes and quality of life. *Br Jnl Psychiatry* 2004; 184: 346-51.

[64] Douzenis A, Seretis D, Nika S, Nikoladou P, Papdopoulou A, Rizos EN, Chrisodoulou C, Tsopelas C, Mitchell D , Lykouras L. Factors affecting hospital stay in psychiatric patients: the role of active comorbidity. *BMC Health Services Research* 2012, 12:166.

3.3 Best practice guidance

3.3.1 NICE Guidance

The National Institute for Health and Clinical Excellence (NICE) produces best practice guidance on a range of health, and in the near future social care, issues. There are several technology appraisals, clinical guidelines, public health guidance and quality standards that relate to schizophrenia, some of which are still in development and will be published over the next couple of years. The NICE schizophrenia guideline[65] (up-dated 2009) covers the treatment and management of schizophrenia and related disorders (schizoaffective disorder, schizophreniform disorder and delusional disorder) in adults with an established diagnosis of schizophrenia and an onset before 60 years. It applies to all healthcare professionals working with people with schizophrenia and their carers. It provides best practice advice for: care across all phases; initiating treatment (first episode); treating the acute episode; and promoting recovery.

The key priorities for implementation identified in the guidance are:

- Access and engagement – ensure healthcare professionals are competent in the skills required to reduce inequalities in access to services (eg take account of cultural and ethnic differences when assessing, explaining causes and treatment options; negotiating skills for working with families; conflict management and resolution); mental health services should work in partnership with local stakeholders to facilitate access to local employment and educational opportunities; and there should be a lead healthcare professional to monitor access to psychological interventions.
- Primary care and physical health – monitor physical health in primary care annually.
- Psychological interventions – offer CBT to all; offer family intervention to all families in close contact with service user.
- Pharmacological interventions – offer oral antipsychotics; choice of drug to be made by service user; combined anti-psychotic medication to be given for short periods only.
- Interventions for people whose illness has not responded adequately to treatment – review diagnosis, adherence to medication, and engagement/use of psychological therapies; offer clozapine in certain circumstances.

[65]National Collaborating Centre for Mental Health. NICE clinical guideline 82. *Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.* March 2009. National Institute for Health and Clinical Excellence.

This guideline is currently being up-dated and will be replaced with the clinical guideline Psychosis and Schizophrenia in adults: treatment and management. The publication date has yet to be confirmed.[66]

NICE recently published guidance on psychosis and schizophrenia in children and young people[67]

NICE have also developed a number of Quality Statements based on the recommendations in the NICE Quality Standard on service user experience[68] which can help to guide and assess service provision.

NICE guidance of relevance for schizophrenia

3.4 Technology appraisals

- TA213 Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years (January 2011)

  http://publications.nice.org.uk/aripiprazole-for-the-treatment-of-schizophrenia-in-people-aged-15-to-17-years-ta213

- Loxapine inhalation for the treatment of acute agitation and disturbed behaviours associated with schizophrenia or bipolar disorder (Expected date of issue: November 2012)
  http://guidance.nice.org.uk/TA/Wave0/632

3.5 Clinical guidelines

- CG82 NICE schizophrenia guideline (up-dated 2009)
  http://guidance.nice.org.uk/CG82

- Core interventions in the treatment and management of schizophrenia in primary and secondary care (update). (Publication date: To be confirmed)
  http://guidance.nice.org.uk/CG/WaveR/113

- CG120 Psychosis with coexisting substance misuse: Assessment and management in adults and young people (March 2011)

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[66] Centre for Clinical Practice. *Scope: Psychosis and schizophrenia in adults: treatment and management*. National Institute for Health and Clinical Excellence.
[67] National Institute for Health and Care Excellence, CG155, January 2013
[68] National Institute for Health and Clinical Excellence.*Quality standard for service user experience in adult mental health*, December 2011.

http://publications.nice.org.uk/psychosis-with-coexisting-substance-misuse-cg120

- CG136 Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (December 2011)

  http://publications.nice.org.uk/service-user-experience-in-adult-mental-health-improving-the-experience-of-care-for-people-using-cg136

- Antenatal and postnatal mental health: clinical management and service guidance (Publication date: to be confirmed)http://guidance.nice.org.uk/CG/Wave0/598

- Psychosis and schizophrenia: recognition and management of psychosis and schizophrenia in children and young people. (Publication date: January 2013)
  http://guidance.nice.org.uk/CG/Wave24/2

- Mental health among prisoners: providing integrated support from the health, social care and criminal justice sectors. (Expected date of issue to be confirmed)
  http://guidance.nice.org.uk/index.jsp?action=byId&o=13726

3.6 Public Health Guidance

- Smoking cessation in secondary care - mental health services (Expected date of issue: November 2013)
  http://guidance.nice.org.uk/PHG/54

3.7 Quality standards

- Quality standard for service user experience in adult mental health (December 2011)
  http://publications.nice.org.uk/quality-standard-for-service-user-experience-in-adult-mental-health-qs14

4 Appendix 4: Schizophrenia – the evidence for what works

In writing this summary of the evidence, we have drawn heavily on the report prepared for the Schizophrenia Commission by the Personal Social Services Research Unit of the London School of Economics " Effective interventions in schizophrenia: the economic case"[69]

A recent report to the Schizophrenia Commission identifies 8 'key cost drivers' associated with schizophrenia

- Inpatient time
- Disrupted / loss of employment
- Disrupted education
- Homelessness
- Physical health problems
- Substance misuse
- Contact with criminal justice system
- Family impact

The interventions considered below respond to these key cost drivers

Where possible, we have indicated the cost savings to the NHS; however it should be recognised that many of the savings are more likely to be seen in other parts of the public sector, or in the wider economy.

4.1 Early Intervention Services (EIS)

Early intervention seeks to prevent the onset of schizophrenia in people with prodromal symptoms and to provide effective treatment to people in the early stages of schizophrenia. Treatment in the early intervention stage typically involves a combination of 'pharmacological, psychological, social, occupational and educational interventions.[70]There is some evidence that a delay in receiving treatment reduces the chances or the extent of recovery.[71]

[69]Andrew A, Knapp M, McCrone P, Parsonage M, Trachtenberg M (2012) *Effective interventions in schizophrenia: the economic case* . London: LSE.

[70] NICE. (2009) Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care. Clinical Guideline 82.

[71] Marshall M, Lewis S, Lockwood A, Drake R, Jones P, Croudace T (2005) Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. Archives of General Psychiatry 62 (9) p975-83.

Early intervention services are widespread in England[72], Europe, America and Australia. A recent systematic review found that specialist first episode psychosis programmes can reduce the risk of relapse when compared to usual treatment.[73] A recent large scale review[74] of services for young individuals at high risk for psychosis in South London (in a catchment area that covers Croydon) offered a pathway of effective diagnosis and treatment.

A 2011 Cochrane review found that the evidence to demonstrate effectiveness was weak[75] but these findings have been disputed on the basis that the methodology was inappropriate and the review excluded many well designed studies that provide evidence of effectiveness of EI services.

A recent study of the potential cost savings of Early Intervention Services[76] to the mental health services are as follows:

- Avoiding formal admission to hospital: £5,493 per service user in the first year of psychosis and £15,742 during the first three years
- Reducing the risk of suicide and homicide: £481 in the first year of psychosis
- Earnings: gain in earning of £4,299
- Net cost savings: a saving to the NHS of £5,536 in the first year of psychosis, rising to £15,862 over the first three years.

(Caution must be used in applying these figures which may be dependent on local practice).

These savings manly reflect reductions in admission and readmission rates.[77]Some studies[78] have shown that the benefits of EIS are no longer seen at a five-year follow up, but that this might be due to service users discharging themselves. The long-term impact of EI is dependent on what

[72]Shiers D, Smith J (2010) *Early intervention in psychosis: a briefing for service planners*. London: National Mental Health Development Unit.
[73]Alvarez-Jimenez M, Parker AG, Hetrick SE, McGorry PD, Gleeson JF (2011) Preventing the second episode: a systematic review and meta-analysis of psychosocial and pharmacological trials in first-episode psychosis. *Schizophrenia Bulletin* 37 (3) 619-30.
[74]Fusar-Poli P, Byrne M, Badger S, Valmaggia LR, McGuire PK (2012) Outreach and support in South London (OASIS) 2001 – 2011: ten years of early diagnosis and treatment for young individuals at high clinical risk for psychosis. *European Psychiatry* 2012 (in press).
[75]Marshall M, Rathbone J. Early intervention for psychosis.*Cochrane Database of Systematic Reviews* 2011, Issue 6.
[76]McCrone P, Park AL, Knapp M (2010) *Economic evaluation of early interventions(EI) services: phase IV report*. PSSRU Discussion Paper 2475.London:LSE.
[77]IRIS initiative.*IRIS Guidelines Update*, September 2012.
[78]Gafoor R, Nitsch D, McCrone P, Craig TK (2010) Effect of early intervention on 5-year outcome in non-affective psychosis.*British Journal of Psychiatry* 192 (6) p412-423.

happens to readmission rates after discharge. However, savings over 8 years are expected even if they revert to those of standard care.[79]

4.2 Treatment in the community

Community mental health teams are widely used to deliver specialist care packages to people in the community; a 2007 Cochrane review did not find overwhelming evidence of effectiveness.[80]

Acute day hospitals are another way of providing community- based care; A 2011 Cochrane review found that day hospitals were as effective as inpatient care, and that at least one in five currently admitted to inpatient care could feasibly be treated in a day hospital.[81]

4.3 Crisis resolution

Crisis Resolution Home Treatment (CRHT) teams were set up in the NHS as they were recommended in the National Service Framework (NSF) of 1999.

Crisis care, where intensive treatment and support is provided during a crisis for service users, either in the home or in a community setting, was found in a small set of studies to be worthwhile, acceptable and less costly than standard care. It had the benefits of reducing hospital admission, placed less burden on service users and their families or carers.[82] Recent studies from Islingtonfound that a CRHT team reduced service user costs by £1,738 - £2,520.[83,84]

[79]NHS Confederation Mental Health Network.*Early Intervention in Psychosis Services.*Briefing, May 2011, Issue 219.

[80]Malone D, Marriott S, Newton-Howes G, Simmonds S, Tyrer P. Community mental health teams (CMHTs) for people with severe mental illnesses and disordered personality. Cochrane Database of Systematic Reviews 2007, Issue 3.

[81]Marshall M, Crowther R, Sledge WH, Rathbone J, Soares-Weiser K. Day hospital versus admission for acute psychiatric disorders. Cochrane Database of Systematic Reviews 2011, Issue 12.

[82]Murphy S, Irving CB, Adams CE, Driver R. Crisis intervention for people with severe mental illnesses. *Cochrane Database of Systematic Review*s 2012, Issue 5.

[83]McCrone P, Johnson S, Nolan F, Pilling S, Sandor A, Hoult J et al (2009) Economic evaluation of a crisis resolution services: randomised controlled trial, *Epidemiologia e PsichiatriaSociale* 18 (1) 54-8.

[84]McCrone P, Johnson S, Nolan F, Sandor A, Hoult J, White IR, Bebbington P (2009) Impact of a crisis resolution team on service costs in the UK. *Psychiatric Bulletin* 33 17-19.

A National Audit Office[85] report of 2007 concluded that CRHT were under-utilised:only 50% of inpatient admissions were assessed by a CRHT team and 20% of the admissions were considered suitable for CRHT. NAO estimated potential cost savings of £13.7 to £59 million if under-performing teams increased their capacity.

These studies were limited in numbers, and were not applied to service users with alcohol or drug misuse or at danger of harming themselves.

4.4 Psychological therapies

Cognitive Behaviour Therapy (CBT) is formally recommended by NICE but is not widely offered. A recent Cochrane review[86] found that CBT reduced readmission rates in the short, medium and long runs. Estimates of the cost-effectiveness of CBT suggest that it is a cost effective treatment for schizophrenia, providing superior clinical outcomes for the same cost although a more recent RCT[87] has found that costs were higher than for standard care, but again that clinical outcomes were superior. A review has found that cognitive remediation therapy (designed to improve neurocognitive abilities such as attention, working memory, cognitive flexibility and planning, and executive function) had a small-to-moderate beneficial effect on cognition in patients with schizophrenia.[88]

Family therapy describes a range of psychosocial interventions for people who have a significant emotional connection to someone with schizophrenia. There is good evidence that psychosocial interventions within families, to reduce expressed emotions (hostility, criticism or over-involvement), will reduce the likelihood of relapse for people with schizophrenia[89] A recent

[85] National Audit Office (2007) *Helping people through mental health crisis: the role of Crisis Resolution and Home treatment services*. London: NAO.

[86] Jones C, Hacker D, Cormac I, Meaden A, Irving CB (2012) Cognitive behaviour therapy versus other psychosocial treatments for schizophrenia. *Cochrane Database of Systematic Reviews* (4).

[87] Van der Gaag M, Stant AD, Wolters KJ, Buskens E, Wiersma D (2011) Cognitive-behavioural therapy for persistent and recurrent psychosis in people with schizophrenia-spectrum disorder cost-effectiveness analysis. *British Journal of Psychiatry* 198 (1) 59-65 Suppl 1.

[88] Wykes T; Huddy V; Cellard C; : McGurk SR; Czobor P (20110 A meta-analysis of cognitive remediation for schizophrenia: methodology and effect sizes American Journal of Psychiatry VL: 168 NO: 5 PG: 472-485

[89] Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database of Systematic Reviews 2010, Issue 12.

modelling of cost savings indicates that family intervention would bring a saving of £1004 over a three-year period[90]

4.5 Other therapies

The literature review considered a number of other therapies. It found evidence of benefit for some, no evidence of benefit for others and insufficient data to reach any definitive conclusion for others.

Evidence of benefit

- Exercise therapy for schizophrenia[91]
- Music therapy for people with schizophrenia and schizophrenia-like disorders.[92]
- Chinese herbal medicine for schizophrenia [93]

No evidence of benefit

- Cognitive behaviour therapy versus other psychosocial treatments for schizophrenia [94]

Insufficient data

- Acupuncture for schizophrenia [95]
- Art therapy for schizophrenia or schizophrenia-like illnesses [96]
- Dance therapy for schizophrenia [97]
- Distraction techniques for schizophrenia [98]

[90] Andrew A, Knapp M, McCrone P, Parsonage M, Trachtenberg M (2012) *Effective interventions in schizophrenia: the economic case* . London: LSE.
[91] Gorczynski P, Faulkner G. Exercise therapy for schizophrenia. Cochrane Database of Systematic Reviews 2010, Issue 5
[92] Mössler K, Chen X, Heldal TO, Gold C. Music therapy for people with schizophrenia and schizophrenia-like disorders. Cochrane Database of Systematic Reviews 2011, Issue 12.
[93] Rathbone J, Zhang L, Zhang M, Xia J, Liu X, Yang Y. Chinese herbal medicine for schizophrenia. Cochrane Database of Systematic Reviews 2005, Issue 4
[94] Jones C, Hacker D, Cormac I, Meaden A, Irving CB. Cognitive behaviour therapy versus other psychosocial treatments for schizophrenia. Cochrane Database of Systematic Reviews 2012, Issue 4
[95] Rathbone J, Xia J. Acupuncture for schizophrenia. Cochrane Database of Systematic Reviews 2005, Issue 4.
[96] Ruddy R, Milnes D. Art therapy for schizophrenia or schizophrenia-like illnesses. Cochrane Database of Systematic Reviews 2005, Issue 4
[97] Xia J, Grant TJ. Dance therapy for schizophrenia. Cochrane Database of Systematic Reviews 2009, Issue 1

- Drama therapy for schizophrenia or schizophrenia-like illnesses [99]
- Supportive therapy for schizophrenia [100]
- Token economy for schizophrenia [101]

Remains experimental

- Morita therapy [102] – This is a form of mindfulness therapy which involves a structured behavioural program to encourage an outward perspective on life and increased social functioning.

4.6 Employment

Most people with schizophrenia and other severe mental illnesses want to work[103] but only between 5% and 15% are in employment.

A 2001 Cochrane review found that there were better outcomes from an approach which placed people in competitive employment (Individual Placement and Support) as soon as possible rather than a pre-vocational training approach that required a period of preparation before seeking employment.[104] IPS tailors support to individual need, provides intensive support to find paid work, followed by unlimited support for both the employee and the employer.[105] IPS has also been shown to improve clinical outcomes.

A recent economic evaluation of IPS indicates a total saving to the National Health Service of £5,193 per service user over 18 months, mostly on reduced in-patient costs.[106] There are likely to be savings in terms of revenue generation for the Exchequer. IPS was largely developed in the USA and

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[98] Crawford-Walker CJ, King A, Chan S. Distraction techniques for schizophrenia. Cochrane Database of Systematic Reviews 2005, Issue 1

[99] Ruddy R, Dent-Brown K. Drama therapy for schizophrenia or schizophrenia-like illnesses. Cochrane Database of Systematic Reviews 2007, Issue 1

[100] Buckley LA, Pettit TACL, Adams CE. Supportive therapy for schizophrenia. Cochrane Database of Systematic Reviews 2007, Issue 3.

[101] McMonagle T, Sultana A. Token economy for schizophrenia. Cochrane Database of Systematic Reviews 2000, Issue 3

[102] He Y, Li C. Morita therapy for schizophrenia. Cochrane Database of Systematic Reviews 2007, Issue 1.

[103]Marwaha S (2005) Views and experiences of employment among people with psychosis: a qualitative descriptive study. *International Journal of Social Psychology* 51 (4) 302-316.

[104]Crowther R, Marshall M, Bond GR, Huxley P. Vocational rehabilitation for people with severe mental illness. *Cochrane Database of Systematic Reviews* 2001, Issue 2.

[105]Centre for Mental Health. Briefing 44.*Implementing what works: The impact of the Individual Placement and Support regional trainer.*

[106] Knapp M, Patel A, Curran C, Latimer E, Catty J, Becker T et al (2012) Supported employment cost-effectiveness across six European sites. World Psychiatry (forthcoming).

there are arguments that the model may not be applicable in the UK because of the structure of the benefits system; the current revision of social security entitlements would need to be taken into account.

Around 25% of mental health trusts are investing in IPS.[107]

4.7 Homelessness and housing

People with schizophrenia are highly vulnerable to becoming homeless, with big implications for their mental and physical wellbeing, for direct service costs, as well as being a waste of economic potential.

There is an argument that dedicated housing schemes supported by professional workers may benefit people with severe mental illness by providing them with a 'safe haven'; but also a countervailing argument that this could result in increased dependence and isolation from the community. A Cochrane review of 2006 did not find conclusive evidence for either interpretation.[108]

Current thinking sees three different approaches to housing for people with serious mental illness: custodial; supportive; supported. Supported housing is increasingly seen as promising good outcomes.[109]

For homeless people with severe mental illness, US programmes have placed emphasis on providing 'housing first', but the argument between 'housing first' and 'treatment first' approaches has remained inconclusive. However, 'treatment first' clients are more likely to use treatment services, whereas 'housing first' clients have greater levels of housing stability.[110]

The 'Critical Time Intervention' (CTI), is designed to reduce the risk of homelessness and other adverse outcomes during the first nine months

[107]The Schizophrenia Commission.*The Abandoned Illness.* Rethink Mental Illness, November 2012.
[108]Chilvers R, Macdonald G, Hayes A. Supported housing for people with severe mental disorders. Cochrane Database of Systematic Reviews 2006, Issue 4.
[109]Nelson, Geoffrey (2010) Housing for people with serious mental illness: Approaches, evidence, and transformattve change.*Journal of Sociology and Social Welfare*, December 2010, vol./is. 37/4(123-146).
[110] Padgett, Deborah K, Gulcur, Leyla, Tsemberis, Sam (2010) Housing first services for people who are homeless with co-occurring serious mental illness and substance abuse. *Evidence-based practice in the field of substance abuse: A book of readings*., 2010(247-260) (2010

following discharge from institutions to community living. An RCT from 1999[111] showed a significant reduction in chronic homelessness; the cost of the service was slightly higher than the control but was almost offset by a reduction in service use. A recent RCT [112]has similarly found a five-fold decrease in the risk of homelessness following discharge from a psychiatric hospital in New York.

Assertive Community Treatment (ACT) (outpatient service model grounded on a mobile team delivering psychiatric care and case management to people with schizophrenia who make intensive use of inpatient services) is an approach that is not specifically designed for homelessness but has been applied to this issue. The evidence suggests that this is not the most cost-effective approach.[113]ACT is deemed to be effective in rehabilitating severely mentally ill patients in community settings.[114]

4.8 Social inclusion

People with severe and chronic mental ill health may struggle with the common activities of everyday life; interventions such as creative therapies, work-based therapy, recreational activities, and life skill teaching have all been shown to have some impact of improvements in the quality of life. [115]

4.9 Social integration

Individual studies indicate that professional support remains important even when clients with severe mental illness have good natural support.[116]

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[111] Lennon MC, McAllister W, Kuang L, Herman DB. (2005) Capturing intervention effects over time: reanalysis of a critical time intervention for homeless mentally ill men. *American Journal of Public Health* 95 (1) 1760-6

[112] Herman D, Conover S, Gorroochurn P, Hinterland K, Hoepner L, Susser, E (2011) A randomised trial of critical time intervention to prevent homelessness in persons with severe mental illness following institutional discharge. Psychiatric Services 62 (7) 713-719

[113] Slade EP, McCarthy JF, Valnstein M, Visnic S, Dixon LB. (2012) Cost savings from assertive community treatment services in an era of declining psychiatric inpatient use. Health Services Research 1 – 23.

[114]Udechuku A, Olver J, Hallam K, Blyth F, Leslie M, Nasso M, Schlesinger P, Warren L, Turner M, Burrows G. (2005) Assertive community treatment of the mentally ill: servive model and effectiveness Australasian Psychiatry 13 (2) 129-34.

[115]Tungpunkom P, Maayan N, Soares-Weiser K. Life skills programmes for chronic mental illnesses. Cochrane Database of Systematic Reviews 2012, Issue 1.

[116] Tsai, Jack, Desai, Rani A, Rosenheck, Robert A (2012)
Social integration of people with severe mental illness: Relationships between symptom severity, professional assistance, and natural support. *The Journal of Behavioral Health Services & Research*, April 2012, vol./is. 39/2(144-157).

4.10 Peer support workers

Peer support is defined as social emotional support that is mutually offered, by persons having a mental health problem to others sharing a similar mental health condition, to bring about a desired personal or social change. Peer support workers will generally receive some formal training. Peer support workers work within the 'recovery' approach - that is the belief that patients can lead normal lives, secure employment, education and training and independent housing, and generally achieve overall wellbeing beyond symptom management. A forthcoming report from the Centre for Mental Health, quoted by Andrew et al[117] found that peer support workers would almost certainly generate net cost savings. It should also be acknowledged that there is an unquantifiable benefit to the improvement of Quality of Life of the peer support workers themselves.[118]

4.11 Reducing co-morbidities and physical ill-health

People with severe mental illness are at higher risk of physical health conditions including obesity, coronary heart disease, diabetes.[119]
There is little robust evidence that providing generalised health information to people with severe mental illness has a long term benefit [120]Specific interventions to reduce weight have found that both pharmacological and psychosocial interventions were effective in preventing and treating weight gain in the short to medium term[121] . There is no reliable model that would show the overall cost savings of weight reduction interventions.

Exercise therapy has been shown to bring an increase in mental and physical wellbeing[122]; however there is not sufficient evidence for the economic impact to be estimated.

[117] Andrew A, Knapp M, McCrone P, Parsonage M, Trachtenberg M (2012) *Effective interventions in schizophrenia: the economic case* . London: LSE.
[118]Sibtz I, Amering A, Unger A, Seyringer ME, Bachmann A, Schrank B, Benesch T, Schulze B, Woppman A. (2011) The impact of social network, stigma and empowerment on the quality of life in patients with schizophrenia. European Psychiatry 26 (1) 28-33.
[119] Schizophrenia Commission (2012) *The abandoned illness*. London. Schizophrenia Commission.
[120]Tosh G, Clifton A, Bachner M. General physical health advice for people with serious mental illness. Cochrane Database of Systematic Reviews 2011, Issue 2.
[121]Faulkner G, Cohn T, Remington G (2007) Interventions to reduce weight gain in schizophrenia.*Cochrane Database of Systematic Reviews* (1).
[122]Gorczynski P, Faulkner G (2010) Exercise therapy for schizophrenia *Cochrane Database for Systematic Reviews* (5).

Schizophrenia is associated with almost a doubling of the risk of tobacco use; however there is little evidence of the effectiveness of any one intervention to reduce smoking and therefore insufficient evidence of cost-effectiveness.
A small scale study has found that people with schizophrenia will not improve their dietary choices or reduce risk behaviours such as smoking just by being in a care environment that supports quality dietary choices and smoking cessation[123]

4.12 Interventions that work in dual diagnosis

Dual diagnosis, where people have a severe mental illness and a drug and / or alcohol problem can present major problems, both in the numbers of people affected and the impact that it can have. People using drugs or alcohol are more likely to experience a detrimental effect on their illness, the way that their medication works and their interaction with the world. They will be more vulnerable to suicide, hepatitis, HIV and homelessness; they are more likely to move into the criminal justice system. A recent NICE guideline[124] addresses the complex needs of this population. There are a number of psychosocial interventions that have been used with people with dual diagnosis but the Cochrane review of 2008 does not show conclusive evidence of the efficacy of any of them.[125]

A study of the economic consequences of an intervention that combined CBT, family intervention, and motivational interviewing showed a net saving to the health services of £1550 for the intervention group but this was a small study so must be treated with caution.[126]

There is some evidence that intensive case management (a client-centred strategy involving assessment, planning, linkage to other services and

[123] Gupta, Avirup, Craig, Tom K. J (2009) Diet, smoking and cardiovascular risk in schizophrenia in high and low care supported housing. *Epidemiology and Psychiatric Sciences*, 2009, vol./is. 18/3(200-207).
[124]National Institute for Health and Clinical Excellence (2011) Psychosis with coexisting substance misuse: Assessment and management in adults and young people Clinical Guideline CG 120.
[125]Cleary M, Hunt GE, Matheson SL, Siegfried N, Walter G. Psychosocial interventions for people with both severe mental illness and substance misuse. *Cochrane Database of Systematic Reviews* 2008, Issue 1.
[126] Haddock C. (2003) Cognitive behavioural therapy and motivational interviewing intervention for schizophrenia and substance misuse: 18-month outcomes of a randomised controlled trial. *British Journal of Psychiatry* 183 (5) 418-426.

community resources) may be beneficial although it has not been shown to reduce drug use.[127]

4.13 Criminal justice system diversion

Large numbers of people with complex health needs end up in the criminal justice system which is an inappropriate setting for mental health care. One prisoner in ten has a severe mental illness such as schizophrenia; most of these are imprisoned for relatively minor crimes or for short periods of time and are therefore not eligible for placement in an NHS Secure Unit. 'Diversion' seeks to ensure that people with mental health problems are identified and directed towards appropriate mental health care. As many sentences are for less than 12 months, a community sentence is more cost effective than a prison term, as it provides more support and reduces re-offending rates. There is evidence of an under-use of Mental Health Treatment Requirements in sentencing.

[127]Hesse M, Vanderplasschen W, Rapp R, Broekaert E, Fridell M. Case management for persons with substance use disorders. Cochrane Database of Systematic Reviews 2007, Issue 4.

5 Appendix 5:– What people think about service provision and how it could be improved

5.1 Clinical provision

5.1.1 GPs

A good GP was seen as an asset. However it was felt that many GPs in Croydon are not sufficiently informed about mental illness and often lack knowledge of the services available in the community. It was suggested that they need better support and training to enable them to do this work effectively.

GPs themselves say that the referral processes to SLaM are slow and that there are often long delays in getting someone they are concerned about assessed. In fact it is often a crisis that provokes a response. GPs want better communication from secondary care, particularly on discharge from hospital, and need more information about prescribed medication, such as the indication for prescribing which could be provided on the discharge proforma. The SLaM Electronic Patient Journey system does not interface with primary care and cannot be accessed via the CCG.

For a secondary care perspective it was felt that GPs did not always respond to their requests for physical health checks. It was also felt that they need to be more willing to take on anti-psychotic prescribing with secondary care supervision.

5.1.2 Crisis provision

It was felt that problems were not always picked up soon enough and then resulted in a crisis. There were concerns expressed that accessing a crisis response was deficient outside 9 -5 PM Monday to Friday, other than via A&E. Some service users commented on the attitude of A&E staff and said they often had to wait a long time to be seen. It was also said that if someone was brought in by ambulance they would not be triaged by the psychiatric liaison team. It was felt that improved access to crisis provision (eg by 'home treatment team' or a crisis centre) would improve outcomes. It was said by SLaM staff that the 'home treatment team' provision was inadequate for Croydon's population and in comparison to the other Boroughs they served.

"I just think everything is geared towards addressing critical need. If I could just talk to people before, be able to say how I feel, it would help so much."

5.1.3 Secondary care provision

Some services provided by South London and Maudsley (SLaM) were considered to be working well: the home treatment team, COAST early intervention service, Croydon Opportunities Service, and the SUN project were identified. Touchstone was also mentioned by one user as was the perinatal service.

5.1.4 Community provision

There was recognition that there were some good care coordinators and community mental health team (CMHT) workers, however there was acknowledgement that such provision was inconsistent.

> *"Sometimes people with serious mental illness receive a good service from the CMHT. This seems to be entirely random and dependent on the dedication of the particular CPN or social worker, as other people receive a terrible service"*

It was felt that there were too few staff in the recovery teams to meet current demand resulting in high caseloads. Several people mentioned the lack of CPNs and social workers, particularly out of hours, and the need for more regular contact. Home visits were seen as particularly important for those who did not attend groups and after recent discharge from hospital. The morale of care coordinators was perceived to be low since the introduction of Clinical Academic Groups (CAGs) into SLaM. This has also resulted in a lot of staff changes recently and users said they wanted more consistency. Specific mention was made of the unwelcoming feel of Tamworth Road resource centre created by the glass partition at reception.

Service users said they want their views to be heard and responded to, and to be able to express their views without fear. They want to be involved in choice about their care and treatment and to be treated with dignity and respect; one person said "as people and not as a problem that needs medicating. There was a request for more staff training (for medical & non-medical staff) to ensure those who are caring for people with severe mental illness are sufficiently skilled to do so.

> *…." constructive engagement with mental health professionals, where they will not just be considering medical interventions but housing, family situations and vocational opportunities as a way to improve mental health. Staffing levels often prevent this in-depth support being provided."*

5.1.5 In-patient provision

There was perceived to be a bed shortage currently which meant that there was sometimes a need for people to be admitted to a private provider or discharged before they were ready. In addition shortages of staff meant there was little time spent talking to patients. There were some specific comments about the Bethlem: the lack of access to the garden except during the two hourly smoking breaks and the perceived lack of meaningful ward activities. People wanted access to arts and crafts, film and as one person put it 'normal stuff'. It was reported that many women are fearful of admission to the Bethlem, due to threatening behaviour of somestaff and other in-patients, and would therefore far rather be admitted to Foxley Lane. However there are very few beds there and this is not an option for those who require sectioning under the Mental Health Act. By contrast, there were said to be few activities available in Ashburton (the male equivalent) and residents seemed to spend a lot of time in the pub. One person suggested that there should be separate in-patient provision for people experiencing their first episode of psychosis.

It was felt that people are often discharged without sufficient support packages in place. Better discharge planning, involving all support agencies, and regular review of discharge plans, was recommended. It was also felt that there needed to be better partnership working between SLaM and the voluntary sector, and more information provided to people about what services were available and how to access them.

One person suggested that everyone should be followed up for at least six months. If people receiving a package of care are to be discharged back into primary care, a review process needs to be established to ensure they are being appropriately supported and the care package does not continue ad-infinitum. Several people reported that they did not understand how CPA works, and it was said that it was not reviewed regularly but only when things went wrong.

> *"A constant check with their medication and general health, home visits are essential and also someone to go in and check if they have electricity, heat and food to keep themselves alive."*

Other things mentioned were the need for better 'asylum case support' and better support for people with dual diagnosis.

5.1.6 Medication

There is a need for regular medication reviews to ensure people are on the most appropriate drug and dosage to control their symptoms and minimise side-effects. However for those people discharged from secondary care, GPs lack the knowledge and experience to change the dosage. Whilst there is a shared care protocol between primary and secondary care for the prescribing of atypical anti-psychotics, this is not currently being put into practice, the reasons for which are unclear. GPs need more training to enable them to be confident about monitoring medication and dealing with side effects particularly for those people on long-acting injectable anti-psychotics. For patients who want to cut down/ stop smoking there is a need to monitor medication as there are interactions between anti-psychotics and nicotine/other cigarette content. It was also felt that people needed help with medication compliance.

5.1.7 Psychological therapies

Psychology provision and behavioural family interventions were listed as assets at the consultation event. However access to talking therapies for people with severe mental illness was thought to be lacking, particularly for people with dual diagnosis. IAPS provision was said to be available only if very stable and CIPTS had long waiting times. One user said that they would like to know more about how the IAPT service is performing in terms of eligibility, waiting times, and effectiveness.

5.2 Provision to promote personal recovery

5.2.1 Carers

It was acknowledged that carers play an important role in caring for people with serious mental illness yet their needs are not routinely assessed (services do not provide an annual carer assessment) and they do not get the information and support they would like/need. Some felt that carers' views and opinions were not always taken into account by staff, yet they have vital information about the person they care for and what they are like when they are well or unwell. There was thought to be a lack of rehabilitation facilities to give carers a break and that availability of such provision in Croydon could reduce hospital admission. It was also suggested that more 'carer surgeries' in hospital, community mental health teams, and GP practices would be beneficial.

"It is the carer that has the job of dealing with the illness on a day-to-day basis, which is extremely difficult and frustrating at times. More consideration needs to be given to carers and their comments considered."

5.2.2 Social support/social inclusion

Voluntary sector provision to improve social support and inclusion was highly valued, particularly by users and carers.Imagine, MIND in Croydon, Rethink, and provision of peer support and mentoring were mentioned specifically when asked about what works well in Croydon.

In general it was felt that more emphasis needs to be placed on the social aspects of life and recovery activities (such as cooking classes, sport, Active MINDS gym, education, vocational opportunities/employment schemes, outings) and other help to move forward. It was also felt that more service users could be empowered to help and support each other. People thought improved access to the voluntary sector and more universal provision would help to reduce hospital admission.

"…..without these (voluntary organisations) many individuals would be very isolated and would not have the support that they need to gain volunteering, work, become a member of social groups, learn new skills and gain a sense of belonging and self esteem."

Voluntary sector provision was seen as being gradually eroded and an increasing emphasis being placed on risk. Hence some services are only available to those 'on CPA' or who are 'FACs' eligible. However, it is reported that at present even those who meet the eligibility criteria are not always being referred by SLaM. This is thought to be due to the lengthy process documentation required to get approval for direct payments/self-directed support. It was felt that a much more responsive personal budget system was required, in terms of timeliness and flexibility to dip in and out, together with reduced paperwork. There are training needs for care coordinators who are reported to be unclear about the paperwork needing to be completed and also the lack of knowledge about available services.

"I think that sustained effort needs to be given to training staff about personalisation budgets ensuring staff are fully committed to delivering this rather than being resistant – either that or there needs to be a re-think about the whole personalisation agenda."

Concern was expressed about the withdrawal of services provided to improve social skills and volunteering opportunities. The time limited nature of some

(eg 2 years for MIND social networking) was seen as unhelpful for people with serious mental illness. And short-term contracts were seen as counter productive in terms of developing trusting relationships between staff and clients.

> *"I believe that if the voluntary sector is cut anymore it will seriously damage our community. Please do not cut it. We value what we gain and not all of us are eligible for personal budgets to buy the services that keep us well"*

More small support groups, user groups, and drop-ins were wanted. As well as providing support, they could often identify service user's problems early and avert crises; those mentioned were the bipolar support group and Voices. Funding for such provision was seen to be lacking. More independent housing with the availability of low level support or floating support was thought to be needed, rather than just being discharged back to primary care.

A few people thought that there was too much emphasis on moving forward and insufficient on dealing with how they are. Some users mentioned that they felt abandoned or a burden on the services if they did not recover. It was suggested that there needs to be access to a safe place to go every day of the week, preferably in the same venue, as not everyone will recover sufficiently to manage without on-going community support. Such facilities could be used as: "a stepping stone to recovery". The day centre model could have been adapted rather than abandoned and service users supported to run them. Voluntary sector services wanted the ability to visit at home, particularly when someone had just been discharged from hospital.

> *"…, there is not nearly enough support for people living with serious mental health conditions who are trying to live their lives but need a bit more support now and then - help is only offered when things have got really bad and hospitalisation may be unavoidable by that stage."*

It was felt that more public education and positive media stories were required to tackle stigma and discrimination.

5.2.3 Housing

Housing shortages in Croydon meant that there was a lack of housing options available which could delay discharge. It was felt there needed to be a range of options from independent living to low, medium and high dependency. More social housing was also wanted.

5.2.4 Benefits

Changes in the benefit system (benefit reviews and readiness to work assessments; impact on housing options) were thought to be taking their toll, yet there was felt to be a lack of provision to advise and support people. Some felt it was the job of care co-ordinators to provide this, others that they lacked the necessary knowledge and skills and hence it would be better done by people specialising in this work.

5.2.5 BME access issues

Stigma, language difficulties and cultural barriers are reported to inhibit some people, particularly Asian women, from accessing services. In addition, many BME people feel their needs are not catered for. There is also reported to be a lack of awareness amongst BME organisations about the provision available to help and support people with mental health problems.

> *"There are many people living in Croydon … who do not speak English. As such they are less able to easily access community support (eg MIND, Imagine etc). it would be really positive if there were more social/support services within the community for this group."*

5.3 System issues

There were a number of issues which can be classified as system issues, in that they relate to problems in one element of provision which impacts on another, resulting in delays or blockages. It was reported that:

- A lack of capacity in the Home Treatment Team means that staff cannot always take on new cases. As a consequence, people remain in the recovery team where the level of input they require cannot be fulfilled putting them at higher risk of hospital admission.
- Recovery team case loads are higher than is considered best practice so people are forced to work reactively rather than proactively with their clients, and those with chronic problems remain in the secondary care system.
- Social issues (eg housing shortages, benefits issues) often prevent people moving on from hospital to a supported placement, which results in bed blocking.
- Bed closures at SLaM have resulted in a bed shortage. Hence people sometimes need to be admitted to a private provider or are discharged from hospital before they feel ready.
- Some people are said to be inappropriately housed in Bed and Breakfast accommodation as there are long waiting lists for social housing; others stay with friends 'sofa surfing'. Such unstable home

situations are thought to result in set backs in people's recovery and make them more prone to relapse.

- Vocational workers in the Community Opportunities Service prefer that SLaM only discharge patients when COS have completed their work. In addition, GPs are often reluctant to take patients back from secondary care, even when they are stable. Hence movement in the system slows down and the service can gradually become overloaded.
- Insufficient social inclusion provision can mean that services quickly become full and prevent some people gaining access.

"I think you should change your priority from keeping people out of hospital, to that of effective diagnosis, treatment and aftercare. If you get this right you'll find that less serious people will need admission."

The reorganisation of services in SLaM resulting from the establishment of Clinical Academic Groups (CAGs) has caused major changes for everyone: GPs, voluntary organisations, community mental health team staff, but particularly for service users and carers. Although they have now been in place about a year, there is still some confusion about how the system works. For instance there seems to be a lack of clarity about access points and how the different elements of service provision relate to each other. However not everyone sees the changes negatively in that SLaM CAG development was listed as an asset at the consultation event.

5.4 Commissioning Issues

There were a number of concerns expressed that relate to the commissioning of services. Several people said there was no clear strategic vision for service provision in Croydon and a need for a pathway perspective starting in primary care. Too much money was thought to be invested in secondary care (SLaM) and too little in the voluntary sector; too much emphasis placed on the medical sector and insufficient in the social sector eg housing, money advice, social contact, employment. There was thought to be a need to involve the voluntary sector with the statutory services to plan provision (including implementation of personalised budgets) and a need to improve service integration. Some said that SLaM decided the way forward and informed the commissioners of their plans; examples given were the development of CAGs and the establishment of the triage ward. It was felt that out of area placements were occurring due to increased demand on beds, but there was a lack of data identifying why GPs refer to secondary care and the reasons for hospital admission. It was felt that there should be outcome measures in place to demonstrate the effectiveness of SLaM provision.

"There seems to be a serious issue about data. How is it possible to commission services to prevent hospital admission if we don't know why people are being admitted?"

5.5 Keeping people out of hospital

Table 1 summarises people's views as to how people might be kept out of hospital. The key things that users and carers thought would help were mental health services that: kept in regular contact with people through home visits; encouraged people to have active interests including voluntary work; listened more and worked in partnership with patients, families and carers. Cuts to services that promote social inclusion, including closure of day centres, were seen as detrimental as was the impact of benefit cuts. Difficulty in accessing services and support before reaching crisis point, and the lack of social workers/ CPNs and out-of-hours provision were also mentioned. Other things people referred to were: inconsistent service provision, insufficient bed capacity, the need for help with medication compliance, and the need to tackle stigma and discrimination.

For the other survey respondents (health and social care professionals, organisations and public) the key challenges mentioned were the perceived lack of resources in mental health services resulting in slow access to assessment and infrequent access to mental health professionals, particularly out of hours; the need for more community support to increase social inclusion; more advice and support for accessing benefits, housing and employment; earlier intervention to prevent people reaching crisis point, including involving families. Hence there was an overlap with service users' and carers' responses. Other things mentioned were the need for better integration of care, more partnership working across the agencies; more training of staff (including the ambulance and police); better discharge planning; better support for people with dual diagnosis and support for people in taking their medication.

Table 1: Key challenges in keeping people with SMI out of hospital

User and carer views	'Others' (Health and social care workers, service providers, public)
Major themes (mentioned by more people)	
• Providing regular contact as a home based service • Encouraging active interests • Better listening and partnership with patients, families an carers • Insufficient access to social workers or CPNs or out of hours service	• Insufficient resources in MH services • More community support • More advice and support for accessing benefits, housing employment • Better integration of care • Earlier intervention • Better discharge planning

• Impact of cuts to services, including closure of day centres	• Support for people taking medication • More training to ensure staff – medical and no-medical - are skilled in caring for people with serious mental illness
Minor themes (mentioned by fewer people)	
• Impact of benefit cuts • Overcoming stigma and discrimination • Supporting medication compliance • Insufficient bed availability • Difficulties in accessing services and support and in doing so before the patient is in crisis • Inconsistency of service provision	• Inconsistency of CMHT • Difficulty to achieve a dynamic care/life balance • Need more home care • Lack of data on why people are admitted to hospital • Service users not well enough informed to manage their condition • A&E not user friendly • Need a good stepped care package outside of hospital • Negative impact of personalisation budgets and restructuring of services • Recognition of physical illness not good enough

Participants at the consultation event made the following key recommendations to prevent hospital admission:

- Expand existing social inclusion services, reducing eligibility so they are more inclusive, preventing delayed access and relapse
- Bring back open access support services seven days a week and out-of-hours
- Ensure consistently good discharge meetings including all involved, and regularly review plans
- Make a prodromal service available in Croydon

5.6 Most important change needed

For users and carers the most important changes in provision that they would like to see were:

- improved support for and inclusion of carers;
- on-going support including provision of day centres/a safe environment; meaningful work and social activities;
- service integration and continuity of care;
- early intervention so as to prevent crises;
- out-of-hours provision.

Other things mentioned were a better patient: staff ratio in hospital, support following in-patient discharge, supported housing, and more psychological therapies.

6 Appendix 6: Read codes used to identify people with schizophrenia on GP practice registers

Read code	Description
E10..	Schizophrenic disorders
E100.	Simple schizophrenia
E1000	Unspecified schizophrenia
E1001	Subchronic schizophrenia
E1002	Chronic schizophrenic
E1003	Acute exacerbation of subchronic schizophrenia
E1004	Acute exacerbation of chronic schizophrenia
E1005	Schizophrenia in remission
E100z	Simple schizophrenia NOS
E101.	Hebephrenic schizophrenia
E1010	Unspecified hebephrenic schizophrenia
E1011	Subchronic hebephrenic schizophrenia
E1012	Chronic hebephrenic schizophrenia
E1013	Acute exacerbation of subchronic hebephrenic schizophrenia
E1014	Acute exacerbation of chronic hebephrenic schizophrenia
E1015	Hebephrenic schizophrenia in remission
E101z	Hebephrenic schizophrenia NOS
E102.	Catatonic schizophrenia
E1020	Unspecified catatonic schizophrenia
E1021	Subchronic catatonic schizophrenia
E1022	Chronic catatonic schizophrenia
E1023	Acute exacerbation of subchronic catatonic schizophrenia
E1024	Acute exacerbation of chronic catatonic schizophrenia
E1025	Catatonic schizophrenia in remission
E102z	Catatonic schizophrenia NOS
E103.	Paranoid schizophrenia
E1030	Unspecified paranoid schizophrenia
E1031	Subchronic paranoid schizophrenia
E1032	Chronic paranoid schizophrenia
E1033	Acute exacerbation of subchronic paranoid schizophrenia
E1034	Acute exacerbation of chronic paranoid schizophrenia
E1035	Paranoid schizophrenia in remission
E103z	Paranoid schizophrenia NOS
E104.	Acute schizophrenic episode (& [oneirophrenia])
E106.	Residual schizophrenia
E10y.	Schizophrenia: [other] or [cenesthopathic]
E10y0	Atypical schizophrenia
E10y1	Cenesthopathic schizophrenia

E10yz	Other schizophrenia NOS
E10z.	Schizophrenia NOS
E122.	Paraphrenia
Eu20.	Schizophrenia
Eu202	[X] (Catatonic schizophrenia) or (catatonic stupor) or (schizophrenic catalepsy) or (schizophrenic catatonia) or (schizophrenic flexibilatiscerea)
Eu203	[X]Undifferentiated schizophrenia
Eu20y	[X] (Schizophrenia: [cenesthopathic] or [other]) or (schizophreniform disorder [including psychosis] NOS)
Eu20z	[X]Schizophrenia, unspecified
X00S8	Post-schizophrenic depression
X761M	Schizophrenic prodrome
XaB8j	Oneirophrenia
XE1aM	Schizophrenic psychoses (& [paranoid schizophrenia])
XE1aO	(Paranoid schizophrenia) or (paraphrenia)
XE1Xw	Acute schizophrenic episode
XE1Xx	Other schizophrenia
XE1ZM	[X]Other schizophrenia

Note: the Read code version used was CTV3. Practices in Croydon use version 2 Read codes that were mapped to CTV3 Read codes when data was imported into the Croydon data warehouse.

7 Appendix 7 evidence of increased risk of physical health problems in people with schizophrenia

Table 2 provides further details of the studies and evidence base behind the estimates given in the "increased risk cited in the literature" column of **Error! Reference source not found.**.

Table 2 studies giving estimates of increased risk of physical health problems and unhealthy lifestyles

Condition / Behaviour	Increased risk	Studies
Obese	0.6 to 2.1 (men) and 3 (women)	A 2006 study[128] found that 28.7% of men aged 18-44 with a SMI were obese (BMI >30) vs 13.6 of the general population; 50.6% of women aged 18-44 with a SMI were obese vs 16.6% of the general population; Research by the Disability Rights Commission that looked at the primary care records of 1.7 million people in the UK found that people with schizophrenia are 60% more likely to be obese [129]
Smoke	2.37	Filik et al (2006)[130] found 65.3% of people with SMI were smokers vs 27.5% of the general population. People with schizophrenia are twice as likely to smoke than the general population.[131]
Have a stroke	2	Disability Rights Commission found that people with schizophrenia are twice as likely to have had a stroke[132]

[128] Filik R, Sipos A, Kehoe PG, Burns T, Cooper SJ, Stevens H, Laugharne R, Young G, Perrington S, McKendrick J, Stephenson D, Harrison G (2006) The cardiovascular and respiratory health of people with schizophrenia. *Acta Psychiatrica Scandinavica* 2006 113 p298-305

[129]Report to the Disability Rights Commission. Health Inequalities experienced by people with schizophrenia and manic depression. Analysis of general practice data in England and Wales. Report prepared by: Professor Julia Hippisley-Cox Professor Mike Pringle Final version submitted: April 2005. Final version submitted: April 2005. Q Research.

[130] [130] Filik R, Sipos A, Kehoe PG, Burns T, Cooper SJ, Stevens H, Laugharne R, Young G, Perrington S, McKendrick J, Stephenson D, Harrison G (2006) The cardiovascular and respiratory health of people with schizophrenia. *Acta Psychiatrica Scandinavica* 2006 113 p298-305

[131]Report to the Disability Rights Commission. Health Inequalities experienced by people with schizophrenia and manic depression. Analysis of general practice data in England and Wales. Report prepared by: Professor Julia Hippisley-Cox Professor Mike Pringle Final version submitted: April 2005. Final version submitted: April 2005. Q Research

[132]Report to the Disability Rights Commission. Health Inequalities experienced by people with schizophrenia and manic depression. Analysis of general practice data in England and

Have diabetes	2.7 to 3	Ten-year cardiac risk estimates in schizophrenia patients[133] found schizophrenia patients had significantly higher rates of diabetes (13% vs 35%) Disability Rights Commission found people with schizophrenia are 3 times more likely to have diabetes.[134]
High blood pressure	1.6	A comparison of ten-year cardiac risk estimates in schizophrenia patients[135] found that schizophrenia patients had higher rates of hypertension (27% vs 17%)
Cancer	1.5 to 2.6	2012 USA study[136] found total cancer incidence was 2.6 times higher. 2010 systematic review[137] found that all cancer SMR of 1.5
Coronary Heart Disease	1.3 (men) 1.5 (women)	Ten-year cardiac risk estimates in schizophrenia patients[138] found that CHD risk was significantly elevated in male (9.4% vs 7.0%) and female (6.3% vs 4.2%0 schizophrenia patients

Wales. Report prepared by: Professor Julia Hippisley-Cox Professor Mike Pringle Final version submitted: April 2005. Final version submitted: April 2005. Q Research.

[133] Goff DC, Sullivan LM, McEvoy JP. Meyer JM, Nasrallah HA, Daumit GL, Lamberti S, D'Agostino RB, Stroup TS, Davis S, Lieberman JA (2005) A comparison of ten-year cardiac risk estimates in schizophrenia patients from the CATIE study and matched controls. *Schizophrenia Research* 80 (1) 45-53

[134]Report to the Disability Rights Commission. Health Inequalities experienced by people with schizophrenia and manic depression. Analysis of general practice data in England and Wales. Report prepared by: Professor Julia Hippisley-Cox Professor Mike Pringle Final version submitted: April 2005. Final version submitted: April 2005. Q Research.

[135] Goff DC, Sullivan LM, McEvoy JP. Meyer JM, Nasrallah HA, Daumit GL, Lamberti S, D'Agostino RB, Stroup TS, Davis S, Lieberman JA (2005) A comparison of ten-year cardiac risk estimates in schizophrenia patients from the CATIE study and matched controls. *Schizophrenia Research* 80 (1) 45-53

[136] McGinty EE, Zhang Y, Guallar E, Ford DE, Steinwachs D, Dixon LB, Keating NL, Daumit GL (2012) Cancer incidence in a sample of Maryland residents with serious mental illness *Psychiatric Services* 63 (7) p714-7

[137] Bushe, CJ, Hodgson R (2010) *Canadian Journal of Psychiatry* 55 (12) 761-7.

[138] Goff DC, Sullivan LM, McEvoy JP. Meyer JM, Nasrallah HA, Daumit GL, Lamberti S, D'Agostino RB, Stroup TS, Davis S, Lieberman JA (2005) A comparison of ten-year cardiac risk estimates in schizophrenia patients from the CATIE study and matched controls. *Schizophrenai Research* 80 (1) 45-53

8 Appendix 8: Glossary to NHS service provision

8.1 Primary Care

8.1.1 What is the role of primary care in mental health?

Research suggests that many GPs feel that caring for patients with severe mental illness is beyond their remit and see their involvement as caring for physical health and prescribing.[139,140]. Yet a recent national study[141] found that almost a third of people with severe mental illness had only been seen in primary care during the year of study (2008/09), over half of whom had a diagnosis of schizophrenia. Most people had one or more GP consultations, the average consultation rate being 4.6 for those in contact with secondary care and 3.7 for those in contact with primary care only. Whilst consultations were more likely to be for physical health concerns, over 40% were for mental health concerns. This was more likely for those in contact with secondary care (47%), but it is of note that 30% of those seen only in primary care consulted GPs for mental health reasons. Almost two thirds of patients had one or more consultations with a practice nurse, which is an opportunity for health education that may be being missed at present. Eighty percent of all consultations during the year were in primary care, but continuity of care was an issue with the strongest predictor being the number of GP contacts. Continuity was also an issue between primary and secondary care in that the outcome of referral was missing for almost a third of patients, around five percent were never seen by mental health services, eight percent were either lost to follow-up or did not attend their appointment and almost one in six had no reason recorded for discharge from secondary care.Unemployed individuals diagnosed more recently were more likely to have contact with secondary care.

[139]Lester HE, Tritter JQ, Sorohan H (2005) Patients' and health professionals' views on primary care for people with serious mental illness: a focus group study. *BMJ* 330: 1122–1128

[140] Bindman J, Johnson S, Wright S, Szmukler G, Bebbington P, et al. (1997) Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views. *Br J Psychiatr* 171: 169–174.

[141] Reilly S, Planner C, Hann M, Reeves D, Nazareth I, Lester H. The Role of Primary Care in Service Provision for People with Severe Mental Illness in the United Kingdom.*PLoS One. 2012;7(5):e36468. Epub 2012 May 15*

8.1.2 Models of primary care mental health services

There are a number of models designed to improve the quality of partnerships at the interface between primary and specialised mental healthcare.

The Policy Implementation Guide provides the following models:

- Named link workers to work at the primary secondary interface
- Specialists providing on-site services in primary care
- Primary care mental health workers who conduct client work, practice team work and wider networking and liaison
- Gateway workers to improve the gateway to specialist services

A more recent example can be found in Sandwell where a collaborative primary care model focusing on mental health and wellbeing has been developed. It is based on the principles of co-location, integration and collaboration. Physical health and mental health are aligned, and people with mild to moderate mental health needs are treated alongside those with psychiatric conditions. The primary care setting has been found to reduce stigma and improve adherence to treatment. The approach integrates acute, primary and secondary healthcare, wellbeing and social care services. A stepped approach to primary care mental health has been adopted; the steps are graduated from low to high intensity and are non-exclusive. The care pathway is integrated to reflect that recovery is built into each step, so that people can be referred back to primary care at any point.[142]

The Welsh Government has developed a National Service Model for Local Primary Mental Health Support Serviceswith the aim of eliminating variability in the core characteristics and qualities of such provision whilst allowing for flexibility in local delivery. These services will provide local access to support for people of all ages who have mild to moderate and/or stable severe and enduring mental health problems.[143]

8.2 Early intervention in psychosis (EIP)

8.2.1 What is EIP?

Early Intervention in Psychosis (EIP) teams were introduced into the NHS in 2001/02 in response to evidence that suggested the length of time of untreated psychosis reduced the chances or the extent of recovery. Early Intervention services (EIS) offer help to service users in the very early stages

[142]NHS Confederation. A primary care approach to mental health and wellbeing: Case study report on Sandwell. The NHS Confederation. 2012.
[143]Welsh Government.Mental Health Wales Measure.*National Service Model for Local Primary Mental Health Support Services*, August 2011. Crown Copyright.

of psychosis with the aim of achieving the highest possible symptomatic and functional recovery and preventing further decline. EIP is a philosophy of care rather than an intervention.[144]

8.2.2 Service model for EIP

The model for EIS teams outlined in the Policy Implementation Guide states that such services are for people aged between 14 – 35 years at first presentation of psychotic symptoms and during the first three years of their psychotic illness. Ideally an EIS should manage 150 new cases per year and have a total caseload of about 450. This should be split into teams each managing 30-50 new cases per year and 120-150 total caseload. It was envisaged that each service would cater for a population of around 1 million. NICE recommends that everyone experiencing a first episode or first presentation of psychosis should be offered EIS, regardless of age or duration of untreated psychosis.

Key features of the EIP approach include reduced caseloads, access to supervision, strong leadership and management support and a team culture that believes in recovery. EIP has been described as "The jewel in the crown of the NHS mental health reform because service users like it, people get better and it saves money."[145]And a recent review of service provision for people with schizophrenia could not find the constant high standards, recovery ethos, co-production and multi-disciplinary team working elsewhere in the secondary care system.

8.3 Community Mental Health Teams (CMHTs)

8.3.1 What are community mental health teams?

Community mental health teams (CMHTs) have been in place for several decades evolving at the same time as mental hospitals were reducing in size. They generally provide assessment and treatment for the population of a defined sector who are referred by GPs or other health professionals. They take a multidisciplinary approach to working, management and caseloads. Most serve populations of 20 000–60 000 and contain psychiatrists, nurses, social workers and other disciplines such as psychology and occupational therapy, and increasingly more specialist members (eg vocational counselors). Such teams are responsible for the on-going care of people who

[144]IRIS initiative.*IRIS Guidelines Update*, September 2012
[145]IRIS initiative.*IRIS Guidelines Update*, September 2012

require specialist mental health provision and provide a key worker/care coordinator function.

8.3.2 Service model

The recommended caseload size for a CMHT is 300-350, equivalent to 35 per WTE. Caseload size has been found to have a direct effect on levels of patient contact (Burns et al 2000). Some CMHTs were replaced by fully integrated primary care liaison teams which supported primary care to provide services to patients with common mental health problems – see primary care section above.

8.4 Assertive outreach teams

8.4.1 What are assertive outreach teams?

Assertive outreach teams (AO) work with people with long term mental health conditions who find it hard to engage with mental health services. They usually have multiple complex needs and a history of high use of inpatient or intensive home based care. People with psychotic illness with fluctuating mental state and social functioning and poor medication adherence are most likely to benefit. From 2000 assertive outreach became a requirement of community mental health provision in the UK. And they are recommended in the schizophrenia NICE guidance.

8.4.2 Service model

Teams usually serve a population of 250,000, but may be smaller in inner city populations, and are open from 8AM – 8PM. They employ staff who mainly focus on assertive outreach and require a broad skills mix. Teams should include a psychiatrist or have regular access to one. Ideally individual case-loads are 10 to12 patients. Interventions outlined in the Policy Implementation Guidance include: assertive engagement, frequent contact (capacity to visit seven days a week), involvement with basics of daily living (eg practical support with shopping, domestic work, budgeting), support to family and carers, delivery and administration of medication, cognitive behaviour therapy, treatment of other conditions (eg substance misuse, depression), help to reduce social isolation and expand social networks, attention to physical health needs, help to access local services, educational, training and employment opportunities, relapse prevention. Around-the-clock availability is

no longer considered essential, particularly in view of the rise of crisis resolution home treatment teams.[146]

8.5 Crisis resolution Home Treatment (CRHT) Teams

8.5.1 What are CRHT teams?

Crisis Resolution Home Treatment Teams provide intensive community treatment and support to people who would otherwise be admitted to hospital. A key function is 'gate-keeping' inpatient admissions, whether informally or under the provisions of the Mental Health Act, to assess whether the crisis could be safely managed with support in the community. Some teams also facilitate early discharge of in-patients from hospital. If the gatekeeping function works effectively then the team should be aware of every in-patient. The intention is to ensure that people experiencing severe mental health difficulties are treated in the least restrictive environment with the minimum of disruption to their lives. The functions of crisis resolution and home treatment are integral parts of the same team: crisis resolution is the outcome of providing home treatment.[147]

8.5.2 Service model for CRHT teams

The model of CRHT outlined in the Mental Health Policy Implementation Guide includes the following principles of care: 24 hour, 7 day a week service; rapid response following referral; intensive intervention and support in the early stages of the crisis; active involvement of the service user, family and carers; assertive outreach engagement; flexible time limited intervention; learning from crisis. Suggested staffing levels are 14 clinical staff per 150,000 population and a caseload of 20-30 service users at any one time. An areas geography, demography and epidemiology, and health and social care boundaries should be taken into account.[148] It has been argued that inner city areas may need larger teams because they are likely to have more people in crisis for a given population as people tend to have more problems and fewer social supports.

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[146]Andrew Kent and Tom Burns.Assertive community treatment in UK practice. Revisiting... Setting up an Assertive Community Treatment Team.*Advances in Psychiatric Treatment* (2005) 11: 388-397.

[147] Bidgett C, Flowers M, Ford K, Hoult J, Lakhani N and McGlynn. *Crisis Resolution Home Treatment: A practical guide.*Edited by Patrick McGlynn.The Sainsbury's Centre for Mental Health, 2006.

[148]Department of Health.The Mental Health Policy Implementation guide

The Royal College of Psychiatrists has recently developed standards for crisis resolution home treatment teams[149] which are currently being used in the pilot phase of a Home Treatment Accreditation Scheme (HTAS). The pilot is due for completion at the end of 2012 and SLaM is one of the pilot sites. The standards focus on 'function', rather than any particular model of service delivery, however one of the proposed standards is: "The service is able to initiate assessment 24 hours a day, 7 days a week".

8.5.3 Debate re need for 24 hour access

There appears to be some debate as to whether CRHT teams need to provide 24 hour cover. Hoult suggests that where this is not available the team cannot claim to gate-keep hospital admissions comprehensively.[147] A report from the Sainsbury Centre for Mental Health states that where services are in frequent contact with severely mentally ill people the need can usually be predicted and met within reasonable hours (9AM-9PM). Hence it suggests that an on-call service will normally be sufficient to meet unpredictable crises which occur out of hours.**Error! Bookmark not defined.**

8.6 Liaison psychiatry

8.6.1 What is liaison psychiatry?

Liaison psychiatry provides psychiatric treatment to patients attending general hospitals, whether they attend out-patient clinics, accident & emergency departments or are admitted to in-patient wards. Therefore it deals with the interface between physical and psychological health.

There is now abundant evidence that medical and surgical patients have a high prevalence of psychiatric disorder which can be effectively treated with psychological or pharmacological methods.

8.6.2 Service model

The recommended service model is dependent on the case load. For a hospital with 650 beds and 750 new self-harm patients per year the recommended team consists of 1 WTE consultant, 4 WTE nursing staff, 1 WTE clinical psychologist and 1.5 WTE administrator.

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[149]Royal College of Psychiatry.The HTAS Standards for Home Treatment Teams - Pilot Edition. March 2012. http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/hometreatmentteams/htasstandards.aspx

The Psychiatric Liaison Accreditation Network (PLAN), hosted by the Royal College of Psychiatry, has produced quality standards for Liaison Psychiatry Services.Members are expected to take part in a self review every year and a peer review every two years.[150]

8.7 Psychological therapy

8.7.1 What is CBT?

Cognitive Behaviour Therapy (CBT) is a short-term talking therapy, typically consisting of between five and twenty weekly sessions. NICE recommend it should be offered to everyone with schizophrenia and can be started in the acute phase or later, including in inpatient settings. However, recent evidence suggests it is not widely offered.[151]

8.7.2 What is family therapy?

Family therapy describes a range of psychosocial interventions for people who have a significant emotional connection to someone with schizophrenia. It is designed to reduce expressed emotions: hostility, criticism or over-involvement.

8.7.3 What is cognitive remediation therapy?

Cognitive remediation therapy is designed to improve neurocognitive abilities such as attention, working memory, cognitive flexibility and planning, and executive functioning which leads to improved social functioning. It has been used in the treatment of schizophrenia with positive results.

[150]Psychiatric Liaison Accreditation Network (PLAN) *Quality standards for liaison psychiatry services*.Third edition.Edited by Mira Soni, Jennifer Webb, Lucy Palmer, Melanie Dupin and Maureen McGeorge.Royal College of Psychiatrists, Ocotbeer 2011..

[151]The Schizophrenia Commission.*The Abandoned Illness.* Rethink Mental Illness, November 2012.

9 Appendix 9: Service mapping using stepped framework

This appendix considers, at the time of writing, what services are available to people with schizophrenia in Croydon. These services are illustrated and interpreted through a perspective of a stepped framework

Stepped framework approach to interpreting service provision

A stepped framework of 1-5 steps was used to group services. Although each step represents an increased complexity of intervention, all 5 steps are interrelated. Steps 1 to 3 are community and primary care focussed with steps 4 to 5 predominantly secondary mental health services focussed (step 4 being primary-community care facing and step 5 in-patient focussed). An outline illustration of this framework can be seen in Diagram x.

Information was collected on local services that identified provision over a 24/7 inclusive of weekend and public holiday period; access-eligibility criteria and charging arrangements if applicable; and provider categories of either NHS, local authority, voluntary or independent. The core focus of the service was categorised, across all steps, using the following themes with italicised text indicating subthemes:

- Accommodation: *advice, support, homelessness, furniture*
- Advocacy: *information advice and support, Mental Health Act*
- Carers: *advice, support and service*
- Drug and alcohol: *advice, support, service*
- Ethnic minority gender: *support*
- Exercise: *variety, walk, cycling*
- Gender: *support*
- Information, advice, signposting: *self-management, service, assessment and referral*
- Social inclusion, recovery and wellbeing: *support , self-help, building confidence, meaningful activity, volunteering, moving closer to employment, education and training*
- Therapy: *talking, drama*
- Treatment and care
- User voice: *consultancy, forum, service*

The observation arising from this exercise indicates that although service provision can be described as an interrelatedness at all steps and categories further work is required to determine:

- The efficacy and cohesiveness of delivery at each step and across steps;
- Whether current commissioning investment is targeted at best value e.g. present emphasis of NHS spend is on steps 4 to 5, is there a rationale for

adjustment to increase focus on steps 1-3 and would such a change offer better value?

- Develop the approach to commissioning for outcomes to inform performance and impact measurement
- Develop a whole system pathway, and associated referral thresholds, for this patient group. Work in this area has the potential to inform commissioning of the degree to which current provision is demand /needs led, and thus influence not only the performance and efficacy of current provision but also the design and delivery of future services as required.

Stepped care framework

Step 5	**Focus** Very severe and complex presentations with risks of life, life to other, severe self-neglect, and vulnerability	**Interventions** Inpatient care	**Provider** NHS-secondary care Independent sector
Step 4	**Focus** Moderate-severe complex presentations	**Interventions** Psychiatric assessment, case management, complex psychosocial interventions, medication, home treatment and crisis, rehabilitation and recovery interventions	**Provider** NHS-secondary care Local Authority Voluntary sector Independent sector
Step 3	**Focus** Mild-moderate 'uncomplex' presentation	**Interventions** Psychosocial, medication, promoting wellbeing and social inclusion interventions	**Provider** NHS –primary care Local Authority Voluntary sector Independent sector
Step 2	**Focus** Recognition of early warning signs/symptoms	**Interventions** Assessment, watchful waiting, promoting wellbeing interventions, information and signposting	**Provider** NHS- primary care Local Authority Voluntary sector Independent sector
Step 1	**Focus** Raising awareness, reducing stigma	**Interventions** Promoting wellbeing and social inclusion interventions, information and signposting	**Provider** NHS-primary care Local Authority Voluntary sector Independent sector