

North of England
Mental Health Development Unit

**Health Needs Assessment of People with Severe
Mental Illness and design and delivery of
associated training**

Sunderland Locality Interim Report

July 2012



Supporting better mental health

Document control: Final version; Oct 2012

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1.0 Introduction and acknowledgements

The North of England Mental Health Development Unit (NEMHDU) was commissioned to assess the physical health needs of people with Severe Mental Illness (SMI) and provide recommendations and training that will improve their physical health and address current health inequalities for this group. The project was carried out across the South Tyneside and Sunderland PCT Localities. This report focuses on the Sunderland locality.

This project was delivered in partnership between the North of England Mental Health Development Unit and the mental health service user and carer groups in the area:

- Sunderland Service Users (via the locality Service User Development Lead)
- Sunderland Carers Association
- North East Together - Regional mental health service user and carer group

NEMHDU was the lead organisation for delivery of this project however all service user and carer facilitation and development input was remunerated.

Acknowledgements

We would like to formally thank the following for their support in carrying out this project:

- Helen Clay, Mental Health Matters, Service User Development Worker - Sunderland
- Sunderland Headlight
- Sunderland Mind
- Washington Mind
- Fulwell Community Resource Centre
- Washington Primary Care Centre
- Sunderland Carers Centre
- Project Steering Group:
 - Catherine Mackereth
 - Jackie Nixon
 - Mish Lorraine
 - Jayne Guppy
 - Lynda Irvine

We would also like to acknowledge all of the commissioners and service providers who took part in the interviews.

2.0 Aims of the project and delivery methods

Aim	Delivery methods
1. Describe the physical health and well-being needs of people with severe and enduring mental illness, with a particular focus on users' views	<p>We developed and delivered five focus groups for service users and carers. Each focus group was facilitated by the NEMH DU programme lead in partnership with a service user/carer from the locality. All focus group attendees were paid an involvement fee and travelling expenses were reimbursed.</p> <p>Questionnaires were developed for service users and carers</p> <p>A period of field research was carried out, consisting of interviews with lifestyle service providers and mental health care professionals.</p>
2. Provide recommendations for commissioners and service providers about services and interventions that will meet these needs	<p>Data and information gathered from the focus groups and field research interviews has been collated into a locality specific report (this report) which is being delivered to commissioners and the project steering group.</p>
3. Develop training for professionals, with a focus on working with people with SMI around their physical health, to be delivered throughout the summer of 2012, to a range of front line professionals, including lifestyle services, housing officer, library workers, primary care nurses, Children's Centre workers	<p>A four day intensive programme of training development will be undertaken, shaping the findings of the report into a detailed training programme. The development group will include service user/carer representatives.</p> <p>Training will be delivered via ten workshops, to be guided by commissioners on the outcomes of the written report. All workshops will be co-facilitated by a service user or carer.</p>
	<p>A final end of project report will then be prepared and delivered to commissioners.</p>

3.0 Desktop Research

In order to provide a context for this study a short period of desktop research was carried out which revealed the following information.

As part of the study we felt it was important to consider the wider determinants of physical health and wellbeing, for example, most medical staff will consider needs in terms of healthcare services that they can supply either in primary or secondary care. Service users and carers, however, may have a different view of what would make them healthier, for example, a job, a bus route to the hospital or health centre, or decent housing.

This view of health needs can incorporate the wider social and environmental determinants of health, such as deprivation, housing, diet, education, employment.

For health and social care systems, health needs assessment provides the opportunity for:

- Describing the patterns of disease in the local population and the differences from district, regional, or national disease patterns;
- Learning more about the needs and priorities of their patients and the local population;
- Highlighting the areas of unmet need and providing a clear set of objectives to work towards to meet these needs;
- Deciding rationally how to use resources to improve their local population's health in the most effective and efficient way;
- Influencing policy, interagency collaboration, or research and development priorities.

Importantly, health needs assessment also provides a method of monitoring and promoting equity in the provision and use of health services and addressing inequalities in health. (Pritchard P, 1994, pp26-28)¹.

It is also important for this study that we understand the population we are studying. The term 'severe mental illness' (SMI) brings together two complex concepts. The first is defined in terms of five groups of disorders from the International Classification of Diseases (ICD):

- schizophrenic and delusional disorders
- mood (affective) disorders, including depressive, manic and bipolar forms
- neuroses, including phobic, panic and obsessive-compulsive disorders
- behavioural disorders, including eating, sleep and stress disorders
- personality disorders of eight different kinds.

¹ Pritchard P. Community involvement in a changing world. In: Heritage Z, ed. *Community participation in primary care*, London: Royal College of General Practitioners, 1994: 26-28

The second component of SMI places the ICD symptoms and disorders within the context of a judgement of behaviour, course and potential vulnerability.

For example:

- active self-injury, food refusal, suicidal behaviour
- threatening or injurious behaviours, drug abuse, severe personality disorder
- embarrassing, overactive or bizarre behaviours
- long-term 'negative' symptoms, such as slowness, self-neglect, social withdrawal
- physical disability, learning disabilities, social disadvantage.

(Health Care Needs Assessments, 2004)²

Choosing Health (DH 2004)³ refers to SMI as particularly relating to bipolar disorder and schizophrenia. However, for the purpose of this study we will use the term severe mental illness at its most flexible, covering a wide range of diagnoses and context.

General physical health

A wide range of mental health conditions are consistently associated with unemployment, less education, low income and standard of living, poor physical health and adverse life events. (Friedli, 2009)⁴.

For example, some people with severe mental health problems experience inequalities in their physical health that can significantly reduce their average life expectancy. (Seymour L, 2003)⁵.

The Disability Rights Commission has given a stark picture of physical health outcomes, stating: "Someone with a major mental health problem is more likely to develop a significant illness such as diabetes, CHD, stroke or respiratory disease than other citizens, more likely to develop it before 55, and – once they have it – more likely to die of it within five years" (DRC, 2006)⁶.

Research by the DRC (2006)⁶ also found perceived negative or discriminatory attitudes of health professionals one of the most significant barriers to healthcare identified by respondents. Sometimes this stigma manifests itself in nurses not taking reported symptoms at face value, but re-labelling them as symptoms of a service user's mental illness.

² Health Care Needs Assessments, Vol2, 2004; Stevens, Rafferty, Mant, Simpson. Sec 13 Severe Mental Illness, John K Wing

³ Department of Health (2004); Choosing Health: Making healthy choices easier

⁴ Friedli, L (2009) *Mental health, resilience and inequalities*. London. Mental Health Foundation & World Health Organisation

⁵ Seymour L, (2003) *Not all in the mind*. London. mentality

⁶ Disability Rights Commission, 2006, Equal Treatment: Closing the Gap. A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems. Stratford upon Avon: DRC

Smoking

Although people with mental health problems are more likely to smoke, recent studies show that they have a similar level of motivation to quit as the general population, and are able to quit when offered evidence-based support (Jochelson and Majrowski, 2006⁷ and Siru et al, 2009⁸). Review-level evidence has confirmed the effectiveness of smoking cessation interventions delivered to people with mental health problems (Campion et al. 2008⁹ and Tsoi et al 2010¹⁰).

Research shows that effective smoking cessation treatment is not routinely offered to people with mental health problems. In addition, there is a lack of support for smoke free policies among mental healthcare staff. Staff are reported to lack specific knowledge about the influence of smoking – and cessation activities – on someone's mental health (McNeill 2004¹¹, McNally et al 2006¹² and Ratschen et al 2009b¹³). Evidence from a survey of clinical staff in one NHS mental health trust identified that more than a third of doctors were unaware that, following smoking cessation, doses of some antipsychotic medications may need to be reduced (Ratschen et al. 2009b)¹³.

In addition, Campion et al (2010)¹⁴ state that interactions between nicotine and some psychiatric medications make the medications less effective so that a higher dose is needed. In some instances, there is a need for a planned reduction of doses of medications during a quit attempt.

Those from routine and manual groups take in more nicotine from cigarettes than more affluent people (Jarvis 2010)¹⁵. This increases their exposure to the other toxins in tobacco smoke and, thus, increases their risk of smoking-related disease. Higher nicotine exposure can also make it harder for them to quit – and they are more likely to cut down first rather than quit smoking abruptly (Siahpush et al. 2010)¹⁶. As a result, people on a low income may need additional support to quit (The Marmot Review Team 2010)¹⁷.

⁷ Jochelson K, Majrowski B (2006) Clearing the air: debating smoke-free policies in psychiatric units [online].

⁸ Siru, Hulse and Tait (2009) Assessing Motivation to Quit Smoking in People with Mental Illness; a review. *Addiction* 104(5) 719-733

⁹ Campion J, Checinski K, Nurse J (2008) Review of smoking cessation treatments for people with mental illness. *Advances in psychiatric treatment* 14: 208–16

¹⁰ Tsoi, Mamta, Webster (2010) Efficacy and Safety of Bupropion for Smoking Cessation and Reduction in Schizophrenia; a systematic review and meta-analysis

¹¹ McNeill A (2004) *Smoking and Patients with Mental Health Problems*. London: Health Development Agency

¹² McNally L, Oyefeso A, Annan J, et al. (2006) A survey of staff attitudes to smoking-related policy and intervention in psychiatric and general health care settings. *Journal of Public Health* 28 (3): 192–6

¹³ Ratschen E, Britton J, Doody GA et al. (2009b) Tobacco dependence, treatment and smoke-free policies: a survey of mental health professionals' knowledge and attitudes. *General Hospital Psychiatry* 31: 576–82

¹⁴ Campion J, Hewitt J, Shiers D, et al (2010) Pharmacy guidance on smoking and mental health

¹⁵ Jarvis (2010) The Authors, *Addiction* - Society for the Study of Addiction

¹⁶ Siahpush et al. (2010) - Socioeconomic position and abrupt versus gradual method of quitting smoking: Findings from the International Tobacco Four Country Survey

¹⁷ Marmot Review (2010) *Fair society, healthy lives*. Strategic review of health inequalities in England post-2010. London: The Marmot Review

In 2005, the Disability Rights Commission (DRC, 2006)⁶ found women with schizophrenia were 42% more likely to develop breast cancer than other women. Smoking is probably the biggest contributing factor to this.

NICE are currently developing smoking cessation guidance:

- Smoking cessation in secondary care; mental health services¹⁸. This guidance is proposed to be split into two sections that will address smoke free policies and smoking cessation in mental healthcare settings. It will cover assessment, care and treatment for people with severe mental illness in hospitals, outpatient clinics and the community, as well as intensive services in psychiatric units and secure hospitals.
- Smoking cessation in secondary care: acute and maternity services¹⁹. This guidance will address smoke free policies and smoking cessation in hospitals and other acute or maternity care settings. It will cover emergency care, planned specialist medical care or surgery, and maternity care provided in hospitals, maternity units, outpatient clinics and in the community.

Currently NICE are in the scoping phase and the guidance is proposed to be published in November 2013.

Weight gain

Obesity is a serious public health concern because it can be both a cause and a symptom of long-term conditions such as coronary heart disease and diabetes. Citrome and Vreeland (2009)²⁰ found obesity is the most common physical health problem in mental illness.

In patients with severe mental illness, as in the general population, obesity is associated with lifestyle factors, eg lack of exercise, poor diet, but also with illness-related (negative and depressive symptoms) and treatment-related factors, including weight liability of certain psychotropic agents.

There is a large amount of evidence that certain medications cause significant weight gain. World Psychiatry (2011, p54)²¹ - reproduced at Appendix 1 - shows the weight gain liability of psychotropic agents used in treating severe mental illness.

Significantly, as described above, obesity can lead to an increased risk of diabetes. Evidence suggests that the prevalence of diabetes mellitus in people with schizophrenia as well as in people with bipolar disorder and schizoaffective disorder is 2-3 fold higher compared with the general populations. The risk of diabetes mellitus in people with depression or depressive symptoms is 1.2 - 2.6 times higher compared to people without depression (World Psychiatry, 2011, p55)²¹.

¹⁸ NICE (2012) Smoking cessation in secondary care: mental health services; scope

¹⁹ NICE (2012) Smoking cessation in secondary care: acute and maternity services; scope

²⁰ Citrome L, Vreeland B (2009) Obesity and mental illness. In: Thakore J, Leonard BE (eds) Metabolic Effects of Psychotropic Drugs. Modern Trends in Pharmacopsychiatry. Germany: Basel Karger

²¹ World Psychiatry 10:1 - February 2011; WPA Educational Module: Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care

4.0 Field Research Findings

4.1 Service user and carer focus groups

A summary of the results from the service user focus groups and carer focus groups can be found at Appendix 2. The following are key points from all focus group findings.

Across the five focus groups delivered in the Sunderland area, these were attended by 12 carers and 41 service users.

The focus groups were semi-structured and based around four key areas, the first of which was around what health and wellbeing services people felt they needed.

There was a high level of awareness of their own physical health needs. Participants were highly motivated and identified needs which generally fell into two main themes:

Specific physical health issues

Focus group participants identified the following as being important to them:

- Smoking cessation
- Weight management
- GP health checks
- Diabetes clinic

Lifestyle/wellbeing issues

Many of the participants identified several issues that impacted on their wellbeing such as:

- Social isolation
- Activities for social and emotional support, and confidence building
- Access to exercise and leisure centres, such as swimming/gym
- Access to less formal activities such as allotments and walking groups

The second key area covered in the focus groups asked participants about their level of awareness of existing health and wellbeing services within their locality. Generally across all focus groups there was a very good understanding and awareness of the availability of such services and participants highlighted the importance of the third sector in signposting and supporting people to access those services.

The third key area covered in the focus group was around barriers that prevented people accessing services. There are two themes - one being that people with long term mental health problems tend to be in the lower income bracket, live in the more deprived areas, and have the related physical health problems of that population, ie poor diet, lack of exercise. Costs of travel to and from venues was prohibitive for most people. The second are the issues specifically related to their mental

health - stigma and lack of understanding and awareness of mental health issues within existing service provision was reported as a perceived barrier.

The fourth and final key area was a 'wish list' question - to identify the one thing that would improve their physical and emotional health. The main themes arising under this area were around tackling stigma and more understanding among service providers of mental health issues, and equipping service users and carers with the confidence and support they need to be physically well. For example, keep fit, healthy diet and losing weight.

The groups strongly expressed the need to work with a person's physical health needs as well as their mental health needs and services should have an understanding of the impact of each on the other.

It should be noted that the focus group facilitators reported the challenge of keeping participants focussed on the above key areas, as the debate frequently turned to the changes in the benefit system and the impact that is having on their lives.

4.2 Service user and carer questionnaires

There were 35 service user respondents and 11 carer respondents to the questionnaires. The service user and carer questionnaires were broadly similar, with some carer specific questions which we will make specific reference to. A full breakdown of responses can be found at appendix 3.

Basic demographics show that the age range of service users was spread across the adult age range, with some exceptions of over 65's, with the majority falling in the 40-59 age group. This differed slightly for carers who were all over the age of 50. There was a relatively equal split across the genders for service users, however carer respondents were predominantly female.

On a positive note, 77% of service users reported having had a physical health check at their GP practice within the last year. 82% of carers reported having a physical health check at their GP practice within the last two years.

23% of service users reported receiving care as part of the Care Programme Approach (CPA).

63% of carer respondents could identify that the person they cared for was receiving care as part of the CPA.

Only 17% of service user respondents said their care plan addresses their physical and wellbeing needs as well as their mental health needs. 50% of carer respondents reported that physical and wellbeing needs were part of the care plan and 50% did not know.

It should be noted that the carer respondents were not necessarily the carers of the service user respondents, which may account for the

discrepancy in the number of service users reporting being on CPA and the number of carers reporting the person they care for being on CPA.

81% of carer respondents knew of their legal right to an assessment of their own needs, however only 27% had received an assessment, and yet 72% identified that their caring responsibilities had a direct impact on their physical health and 90% reporting a direct impact on their emotional health and wellbeing.

Of the service user respondents 34% report being smokers, with 0% wanting any help with this issue. 63% of service user respondents report being non-smokers (1 non-responder). Whilst 34% is above the national average of 21% (NHS Information Centre, 2010)²², it is perhaps not as significantly high as might have been anticipated. No carers reported themselves as smokers.

Of all of the respondents who have reported being non smokers 18% also reported that they had used or are using smoking cessation services.

20% of service users reported drinking more than the recommended limits and again 0% reported that they wanted support to tackle this. 0% of carers reported drinking more than the recommended limits.

Of the service user respondents only 22% and 28% respectively felt that they drank or smoked more during periods of increased mental ill health. However between 62% and 71% of service user respondents report exercising less, not sleeping well and worsening of existing physical health conditions during such periods.

72% of service user respondents felt that their confidence dropped during periods of increased mental ill health; 63% reported not visiting friends and family as much, stopping doing their hobbies and staying in bed a lot longer than usual, whilst 48% report a drop in the number of visitors they receive.

37% of service users reported being overweight but not requiring any help to deal with this. However 43% reported being overweight and would want help to deal with this. This is also reflected in the carer respondents where 63% reported being overweight and would want help to deal with this.

An average of 25% of service user respondents had used or were currently using stop smoking, exercise or weight management services, with a slightly higher level (32%) of carers reporting using these services. The majority of people were aware of these services.

When asked if they had thought about using a service but not used it, why that was, we received a range of responses with some quoting costs, others reporting confidence or motivational issues, with one

²² NHS Information Centre, 2010; Statistics on smoking: England 2010. Leeds; NHS Information Centre

respondent being unable to attend a weight management service at the given time slot.

The voluntary sector is playing a significant role in supporting service user and carer health and wellbeing, with over 65% of service user respondents having regular (daily or weekly) support from this sector, with the other mainstay of regular support being family (74%). This is further reinforced by carer respondents, of whom 91% report receiving regular support from the voluntary sector and 54% receiving regular support from family. This compares to 37% of service user respondents and 9% of carer respondents receiving support from mental health professionals.

37% of service user and 63% of carer respondents report having had no contact with job centre, education or training centres.

When service users described the main things that help them to stay physically and emotionally well and happy the themes of family and third sector support as well as contact and activity within local communities were commonly reported.

When reporting what additional support would help with their physical health and emotional wellbeing 34% and 45% of service user and carer respondents respectively indicated that meaningful activity in the form of employment or voluntary work would be helpful, and 45% and 63% respectively indicated that meaningful activity in the form of hobbies would be helpful. In responding to this question carers were reporting what they felt would be helpful for the person they care for, rather than themselves.

62% of service users and 63% of carers indicated that it would be helpful to understand the mental illness that they or the person they care for suffer from, and its potential effect on their physical health and wellbeing.

4.3 Interviews

From across the two areas of Sunderland and South Tyneside we have managed to access the full range of service provision but within the time constraints of the project it was not possible to access the full range of provision within each locality. 17 people in total were interviewed. The collated, anonymised results can be found at Appendix 4.

The interviews were structured around three key questions, the first of which being about what the interviewees think are the physical health and wellbeing needs of people with severe mental illness.

There were a number of assumptions and perceptions amongst health professionals about people with severe mental illness, for example an assumption that most service users smoke, however our research suggests that this is not the case in the Sunderland locality, although in

comparison with national statistics (70% of patients in psychiatric units smoke tobacco - NICE, 2012)¹⁸ this may be an anomaly in this research, and is not reflected in the data from the other geographical locality within this project.

There is a real issue around the prescription of certain medications and weight gain which was recognised by a range of professionals however it was also recognised that there is a large degree of complacency and acceptance that this will happen, with only a few examples (EIP) where this is actively worked on.

Health Trainers currently run a weight management programme at Headlight which is well subscribed. However, it is a rigid 12 week plan and does not suit people if they become unwell during the programme.

There is a perception amongst professionals that the mental health 'label' continues to be a barrier to people having their physical needs addressed. Non-mental health professionals see the mental health 'label' and don't go beyond that, and mental health professionals focus on the mental health problem, so physical needs are not being met either way.

Another consistently identified perception was that people with severe mental illness tend to live in the poverty end of the spectrum and therefore face all the issues of other people in that situation, such as poor diet, lack of finance, etc.

Lifestyle service providers reported a high level of drop-out and non-attendance from people with severe mental illness and this does not fit with the current service provision of 'one strike', eg. smoking cessation prescriptions. There is currently no capacity to work with people on a long term basis. A further issue is that due to the way physical health services are commissioned, ie. from which pot of money are they funded, performance targets are focussed almost exclusively on that area eg. services funded from obesity monies will have targets focussed on reduction in obesity levels.

There is also a perception that mental health service users do not want to change.

The second question was around what the perceived barriers are for people with severe mental illness accessing services to address their physical and wellbeing needs.

Access to services is an issue as there is an expectation that people will go to services, rather than services going to them. Lifestyle service providers acknowledged that a lack of confidence and knowledge of mental health problems was a potential barrier for them in engaging effectively with mental health service users and carers.

Capacity within CMHTs was reported as an issue in that as teams had so little capacity those people best placed to engage in wellbeing activities,

ie. those whose mental health was stable, actually receive the least amount of contact from the teams.

Health Trainers identified a barrier of not using health plan outcomes as a performance indicator and merely being measured on service level outcomes.

The third question asked lifestyle providers what kind of changes they thought were needed to encourage people with severe mental illness to access their services.

Many of the professionals felt that the development of specific targets around physical health needs of people with severe mental illness would help the system focus on those outcomes. It was also suggested there was a need to engage in conversations with commissioners of lifestyle services to review performance targets, as many of the current targets focus on specific success rates which does not encourage service providers to engage with challenging groups. For example smoking targets could be around smoking fewer cigarettes rather than complete cessation.

There were some ideas around putting physical health trainers in community mental health teams. There were also suggestions for health trainers to have a short term focus on mental illness.

It should be noted that many of the lifestyle providers highlighted the necessity to take services to the people rather than have people come to their services.

All interviewees acknowledged the need for confidence and knowledge training for lifestyle service provider staff. Lifestyle service providers have also expressed a lack of understanding of referral and support routes around mental health care. The exercise on referral team in Sunderland also currently collect GHQ12 data (general health questionnaire) which is a measure of current mental health, on all clients referred to their service, as well as a tick box selection indicating whether that person has a severe mental illness or anxiety/depression. On interview we were asked 'so what do I do if they score 23', and had no knowledge of CPNs. The GHQ12 information has never been reviewed, collated or requested by any of the service commissioners.

4.3.1 Health Champions

It was not possible to secure an interview with the Sunderland Health Champions within the timescale of the research, however it is important that they are recognised within this project.

Health champions are recruited from a range of different employers who then receive training and support to enable them to advise other people about health and signpost them to relevant services, as part of their usual work roles. This is an effective way of promoting health, through circles of influence. Health Champions are encouraged to support, inspire and help family, friends, neighbours and clients to lead healthier lives.

5.0 Summary

Service users are telling us that when they are well they are in contact with friends and family, attending social and physical activity, usually via third sector organisations and it is during these times they feel most confident and motivated to meet their physical health needs. However issues of stigma and lack of understanding limit their opportunities. They feel bringing those services to the places where they feel safe and motivated would work better, and offer more flexible access.

During periods of increased mental ill health service users experience a drop in confidence and motivation resulting in increased social exclusion which further impacts on their physical health.

There is consensus amongst all respondents that there is a real issue of cost for all people with severe mental illness accessing services; this is mainly due to the fact that people from this group tend to be on benefits or low income.

A lack of confidence and understanding within the current lifestyle services about mental health is acknowledged as an implicit barrier to working with people with severe mental illness.

Service users also report a desire to better understand their mental illness and its impact on their physical health.

Service users and carers also reported that poor communication between services or services not being joined up often led to being passed on to another service. This may indicate that physical care is not an intrinsic part within a mental health care pathway.

There is a lack of focus within current service provision on physical health needs and an acceptance that current lifestyle service providers require some support and training in the field of mental health.

6.0 Recommendations

1. We recommend that commissioners work on developing a CQUIN target for mental health service providers to ensure that each individual who receives prescribed psychotropic medications that are known to cause weight gain (see Appendix 1) must be offered a weight management programme as part of their treatment. This should apply to new and existing prescriptions.

The current commissioning of smoking cessation services will change in January 2013 to allow any service provider to provide smoking cessation services under contract and receive payment.

2. We recommend the commissioners work with current statutory providers of mental health care to ensure smoking cessation is offered as part of the care pathway.
3. We recommend commissioners working alongside third sector service providers, to develop business plans to ensure mental health services are in a state of readiness to maximise the opportunity of smoking cessation services re-provision.
4. We recommend that commissioners undertake a mapping exercise of all lifestyle services and referral pathways, to understand what is available and the eligibility criteria and patient flows within the system; to explore the blocks and enablers for people with mental health problems using lifestyle services.
5. We will continue to develop a training programme for lifestyle providers to increase confidence, skills and knowledge in working with people with mental health issues. We recommend the commissioners consider targeting a portion of that training at specific lifestyle services as we feel this will have a much greater impact working with teams rather than mixed groups.
6. We recommend that some resource is allocated to reviewing existing mental health information within the exercise on referral programme, ie. information gathered from GHQ12 questionnaires.
7. We recommend that the commissioners initiate discussions with Local Authority colleagues on the update and outcomes of carers assessments. This may result in the need to commission additional capacity to ensure this process meets the needs of local carers.
8. We recommend that the commissioners communicate with Medical Directors at the local Foundation Trust to ensure they are aware of the scoping document for the NICE smoking cessation in mental health guidelines, and in particular the links between prescribing levels and smoking cessation.

9. We recommend that the commissioners of this project explore with lifestyle service commissioners and mental health commissioners the possibility of changing performance targets or focussing resources towards the mental health community, for example, the exercise referral team in Sunderland already has one worker who focuses on maternal health - this could provide a model to have one worker focussing exclusively on the mental health community. Consideration on how this capacity would be resourced would be needed.

7.0 Areas for future discussion

- 7.1 One of the most common themes identified by service users and carers and also professionals was the cost implication of accessing services such as exercise on prescription and other wellbeing activities. For instance, if a person needed medication to improve their life and social wellbeing that medication would be free at point of contact dependent upon whether the person is receiving benefits. Currently, this is not the case with schemes such as exercise on prescription, which is time limited and only provided at a reduced subsidised rate, not free of charge, therefore excluding many people from the most disadvantaged and marginalised groups.

It is identified that people with multiple disadvantage, specifically long term severely mentally ill, have a lower life expectancy. We suggest that commissioners could explore the disparity between the availability of free medication and the lack of availability of free lifestyle services, both of which are acknowledged to have an impact on increasing life expectancy and quality of life.

- 7.2 During the research phase there was a query raised about whether health trainers could be used in a different way within the system to focus on the needs of people with mental health problems. This would require further discussion to fully understand what recommendations could be made.

8.0 Contact Details

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Appendix 1

Weight gain liability of psychotropic agents used in SMI

Drug Class	Weight loss	Relatively weight neutral	Weight gain
Antidepressants	Bupropion Fluoxetine	Citalopram Duloxetine Escitalopram Nefazodone Sertraline Venlafaxine	<i>Substantial:</i> Amitriptyline Imipramine Mirtazapine <i>Intermediate:</i> Nortriptyline Paroxetine
Anticonvulsants/ Mood stabilisers	Topiramate Zonisamide	Lamotrigine Oxcarbazepine	<i>Substantial:</i> Lithium Valproate <i>Intermediate:</i> Carbamazepine Gabapentin
Antipsychotics	Aripiprazole (in pre-treated individuals) Molindone (in pre-treated individuals) Ziprasidone (in pre-treated individuals)	Amisulpride Aripiprazole Asenapine Fluphenazine Haloperidol Lurasidone Perphenazine Ziprasidone	<i>Substantial:</i> Chlorpromazine Clozapine Olanzapine <i>Intermediate:</i> Iloperidone Quetiapine Risperidone Thioridazine Zotepine

From: World Psychiatry 10:1 - February 2011; WPA Educational Module: Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care, p54.

Appendix 2a

Service User Focus Groups - summary of responses

<p>Q1. What health and well being services do you think you need?</p> <ul style="list-style-type: none"> • Gym/exercise +++++ • Allotment/green gyms +++ • Stop smoking +++ • Walking groups + • General social inclusion ++++++ • Weight management +++++ • Swimming/leisure centres +++ • GP health checks + 	<p>Q2. Tell us what health and well being services you are aware of in your area</p> <p>Good awareness of:</p> <ul style="list-style-type: none"> • LA leisure centres ++ • Stop smoking services ++ • Weight management/healthy eating +++ • GP health checks - BP, heart etc + • Alternative therapies eg. relaxation etc ++ • Diabetes clinics ++ <p>Much mentioned re social wellbeing:</p> <ul style="list-style-type: none"> • Art • Fishing • Walking • Cycling <p>Majority provided by third sector organisations ++++++</p> <ul style="list-style-type: none"> • Substance misuse
<p>Q3. What are the barriers that stop you using these services + what are the good points of services?</p> <ul style="list-style-type: none"> • Costs - travel - subsidised rate ++++++ • Support to access ++++ • Services need to be where you are (location) ++++ eg. healthy eating, smoking • Lack of awareness of services re mental health issues +++++ • Stigma ++ • Lack of confidence/motivation +++ • Hard to access IAPT • Poor communication between services +++++ 	<p>Q4. If you had one wish to help you improve your physical and emotional health, what would that be?</p> <ul style="list-style-type: none"> • Support: services+++, family +, peers • Confidence +++ • Motivation ++ • Recovery promotion and awareness ++ • Less stigma, more understanding • Quicker GP referrals and shorter waiting times for talking therapies +++++ • Be physically well +++++ <ul style="list-style-type: none"> - keep fit - healthy diet - lose weight

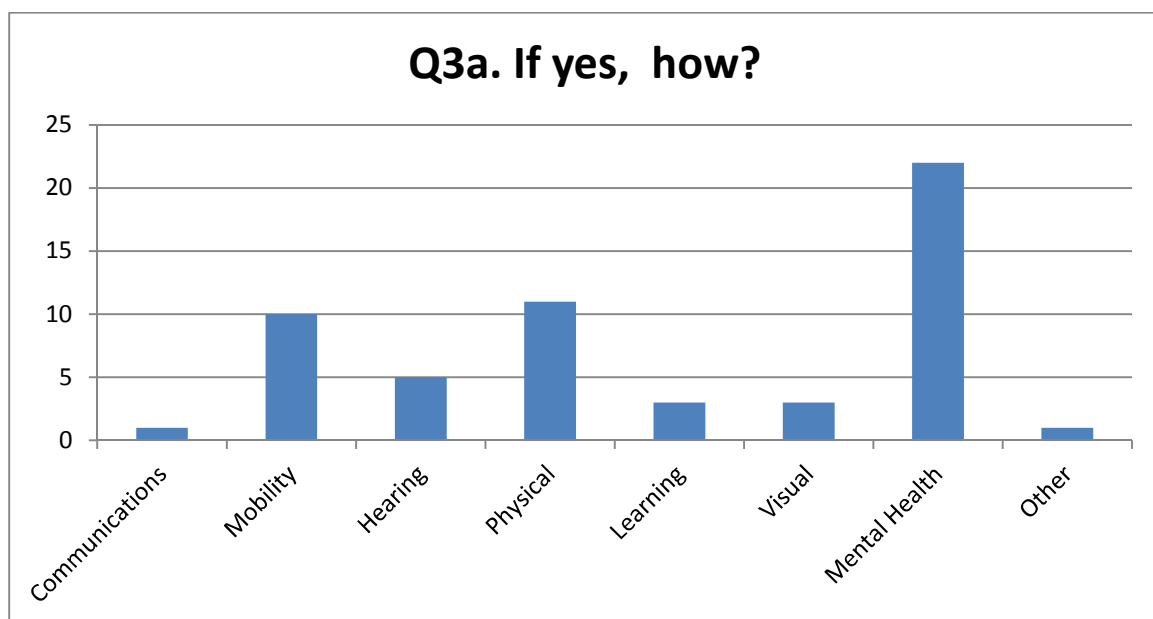
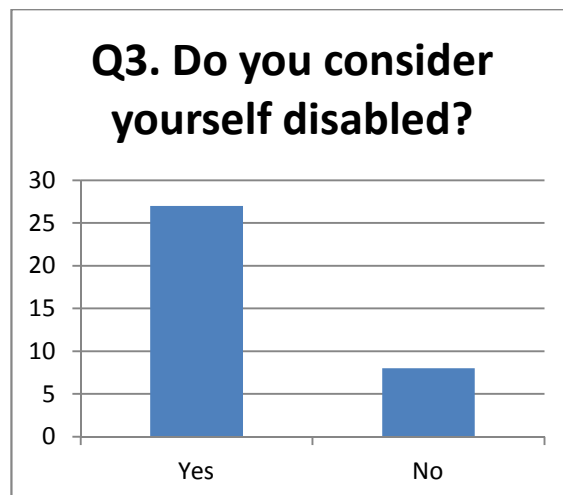
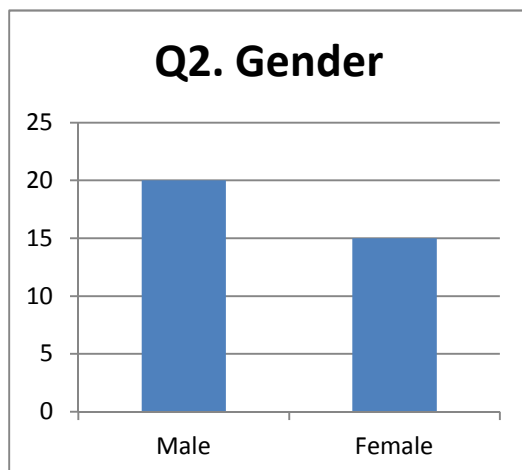
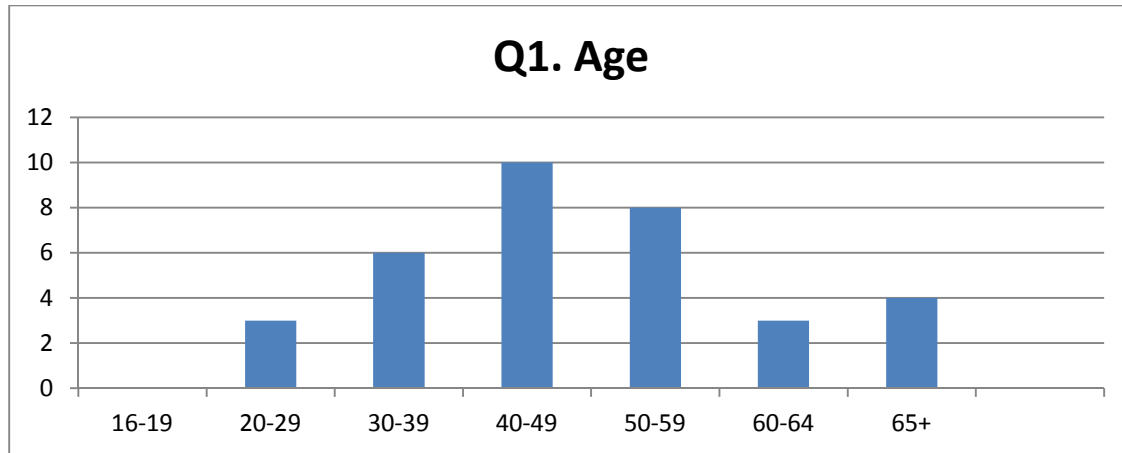
Appendix 2b

Carer Focus Groups - summary of responses

<p>Q1. About you: What health and well being services do you think you need?</p> <p>Gym/physical exercise:</p> <ul style="list-style-type: none"> - swimming ++ - GP health checks, eg blood pressure <p>Lifestyle:</p> <ul style="list-style-type: none"> - social isolation - stress management - activities for social and emotional support - confidence building - stress ++ 	<p>Q2. What health and well being services have you accessed. If not, why not?</p> <p>Physical and GP health checks</p> <ul style="list-style-type: none"> - diabetes clinics - COPD clinics - swimming +++ <p>WHY NOT:</p> <p>Services:</p> <ul style="list-style-type: none"> - lack of understanding of carer role - no information - confidentiality used as a barrier - GP appointments - need to book well in advance to get someone to look after the person you care for - too long from referral to service pick-up <p>Lifestyle:</p> <ul style="list-style-type: none"> - lack of carer support to release me to go - cost of swimming
<p>Q3. The person you care for - what services do you think would help their health and wellbeing + what are the barriers?</p> <p>Lifestyle:</p> <ul style="list-style-type: none"> - Allotment - good exercise for both of us - Arts and creative writing - Social activities <p>Physical:</p> <ul style="list-style-type: none"> - Exercise on prescription - but this was time limited + cost +++ <p>Services:</p> <ul style="list-style-type: none"> - A lack of passing over information ++ - Confidentiality feels like a barrier ++ - Third sector organisations positive ++ 	<p>Q4. If you had one wish for a service to improve your health and wellbeing, what would that be?</p> <p>Services:</p> <ul style="list-style-type: none"> - Better communication - Better understanding of confidentiality as a positive tool not a barrier - Better understanding of carers role +++++

Appendix 3a

Service User Questionnaires - collated responses



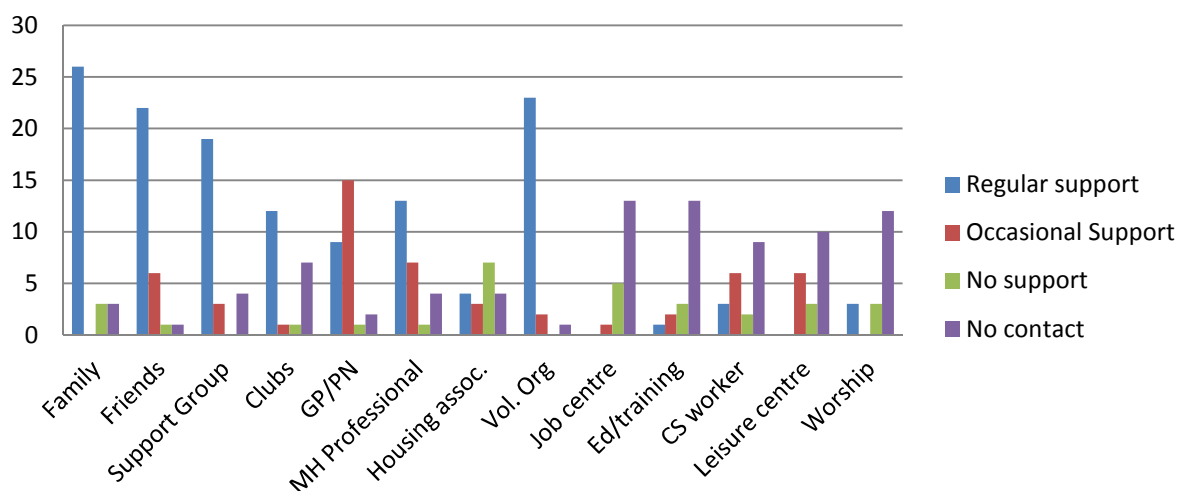
Q3a cont - Please give further details if you wish:	Different from the 'norm'
	I don't consider myself disabled but I do have problems like understanding and filling in forms and that
	Diabetes (Type 2)
	50% in one ear - other damaged
	Emphysema - poor breathing 50-60% lung capacity Bi-polar - mood swings etc

Q4. Please tell us the three most important things to you that help you stay physically and emotionally well and happy

1	2	3
Support from CPN & psychiatrist	Not to worry about day to day living	
Being with people	Talking to people	Being with my family
Family, Headlight	Friends	Walking
My partner	Palliative care	Going to Headlight
Health	Keeping well	
Although fed up with taking medication it does keep me on the straight and narrow	A very positive is the visits to Headlight being around friends and people who are worse and better than myself	With becoming Chairman at Headlight and I do get around to all different meeting with different groups of people
Being with friends	Getting out more	Going to Headlight
Keeping in contact with other people		
Healthy sex life	Exercise	Plenty of nice food
Smoking	Drinking	Fatty food/fast food
Socialising within an organisation such as mental health services (Headlight)	Physical exercise	Weight management group (healthy eating)
Going to Headlight		
Attending Headlight on a daily basis	Socialising	
Cigarettes	Money	Friends
Mixing with friends	Women's group	Smoking
Exercise - get sweaty!	Sex - get intimate!	Laughter - get silly!
Sobriety from alcohol (I've been to the gates of hell. Now the only gates I will be entering are the gates of heaven)	Regular contact either chance meetings or planned	Positive mental attitude. My Christian faith
Friends	Good weather	Being able to get out
Money	Gas on	Somewhere secure to live

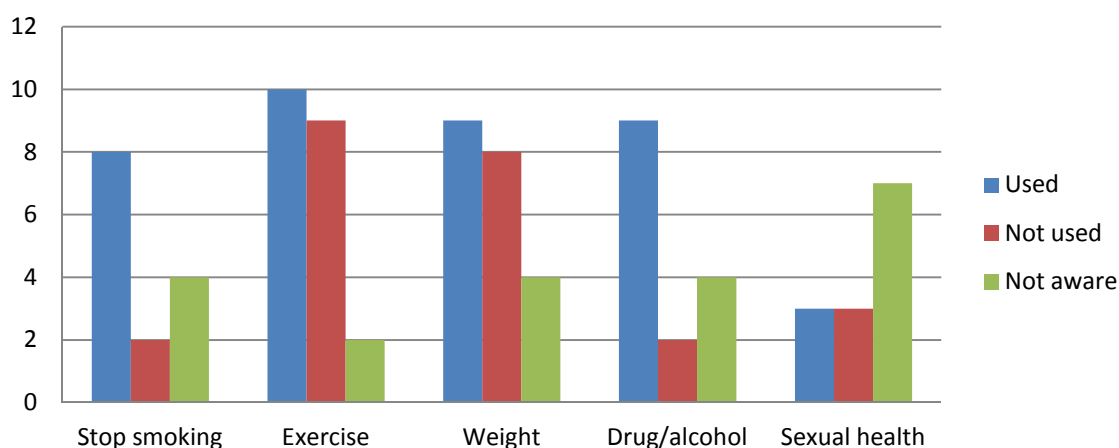
1	2	3
Coming to Mind day services	Meeting new people and doing activities at Mind	Going places and seeing my family
Being with friends & family	Going for walks with my child	
Spending time with family, friends and grandchildren		
Exercise - it would improve my moods	Contentment. I feel that there is overemphasis on the word 'happy'. Contentment should be the word to emphasise on.	To deal with my mental health
My cats	Books	Vodka
My animals - being able to walk them	Friends & family	The right support, ie. Washington Mind
Friends and social activities	Family	Reading
Good support network	Mental health professionals who listen/work with me	Access to other services such as Washington Mind
Stress free life	Socialising	Walking as the sole source of physical activity
Granddaughter's well being	Few problems - good outlook	Breathing reasonable
Regular contact with friends/children	Getting out of the house	Support from CPN
Attending the drop-in		
Family	Washington Mind	Sunshine

Q5. Who do you have contact with/support from to help you keep physically & emotionally well and happy?



Q5 - cont. Other - Regular:	Music
	Women
	Good unhealthy food
	Washington Mind
	Sunderland PD group
	I am an Age Concern volunteer
	Gym
Other - Occasional:	NHS weight management group

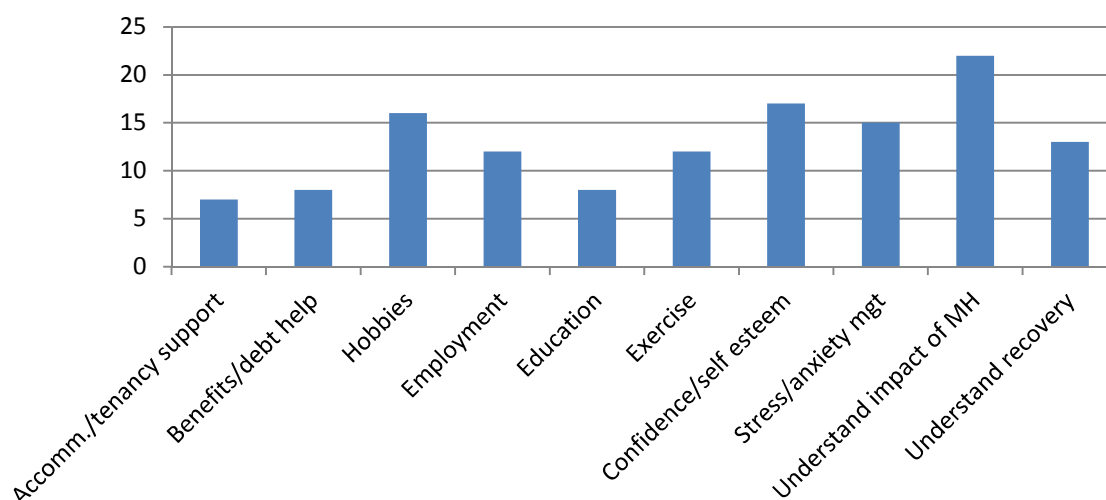
Q6. Please tell us if you have or are currently using, or have thought about using, any of the following lifestyle services:



Q7. If you have thought about using a service but not used it, please tell us why that is:

Service	Reason for not using
Stop smoking	I have already packed in smoking myself
Stop smoking	Was OK. Started smoking again
Weight management	Not able to make the time slot (was at work)
Exercise sessions	Cost
College	Cost
Exercise/weight	Struggle with these issues
Exercise session	Anxiety issues with regards to groups and new people
Drug & alcohol	Too embarrassed

Q8. What other support would help you with your physical and emotional wellbeing?



Q9. If there was one thing that we could do to make it easier for you to live a healthier and happier lifestyle, what would it be?

Give me a new brain

To be with people

Win lottery

To stop worrying about my illness

Live on a desert island. Enjoy being on my own (my own hammock)

Smoking

Good health

Stop the DWP bullying vulnerable people like the mentally ill. They stop people's money to get their bonus - even when the person is far too poorly to work. Disgraceful.

My own flat with 2 bedrooms - one bedroom for me, one bedroom for my partner

More company

Access to cheaper exercise and activities and cheaper healthy foods

Cheaper exercise and cheaper healthy food

Free plastic surgery

Just to feel well and to be a lot happier with myself

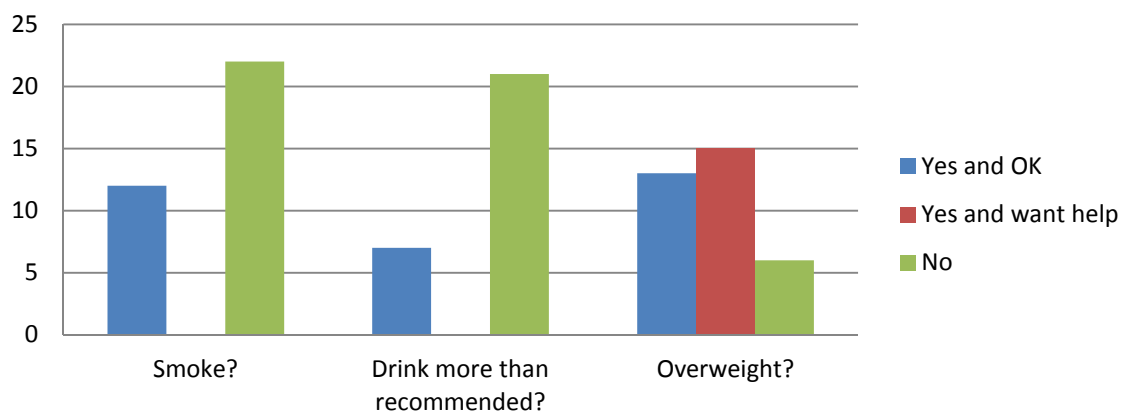
Work on socialising outside of MH facilities to help with social phobia

Stability in my mental health

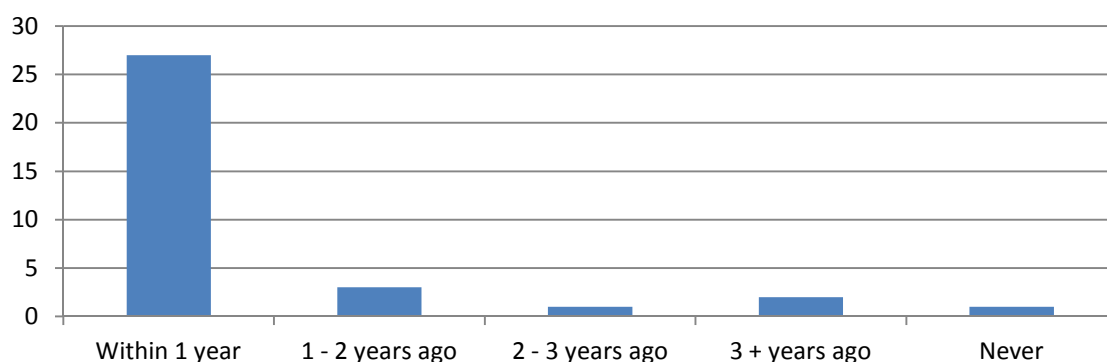
More money

To me a home

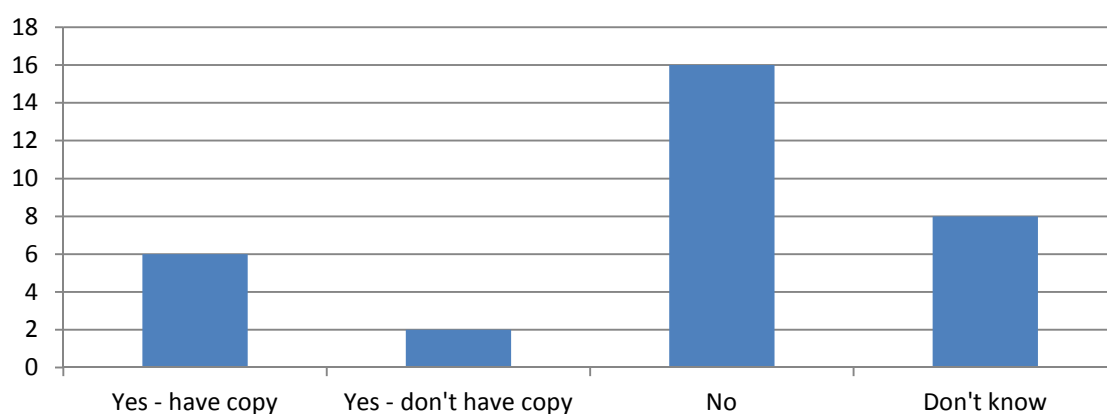
Q10. About your physical health



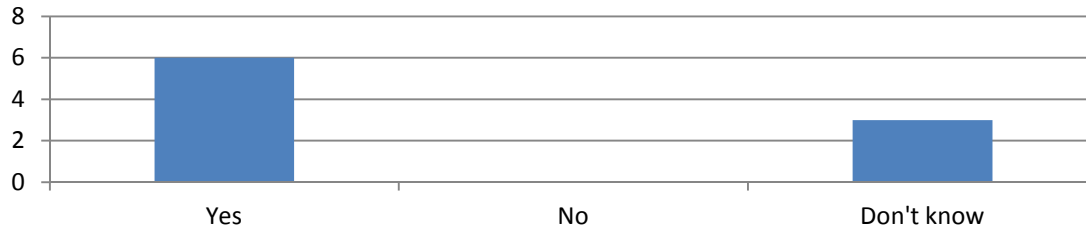
Q11. When did you last attend your GP for a physical health check?



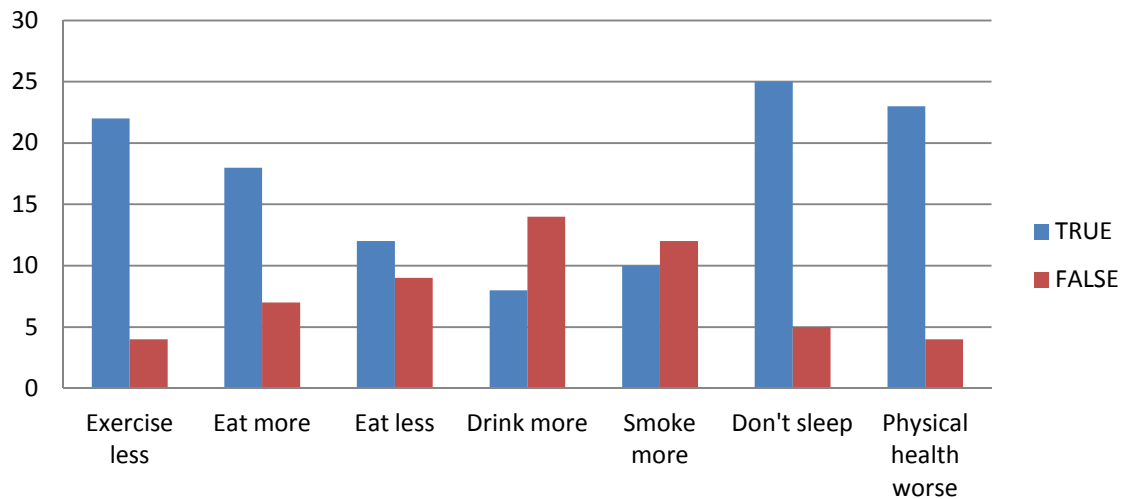
Q12. Do you receive care as part of the Care Programme Approach (CPA)?



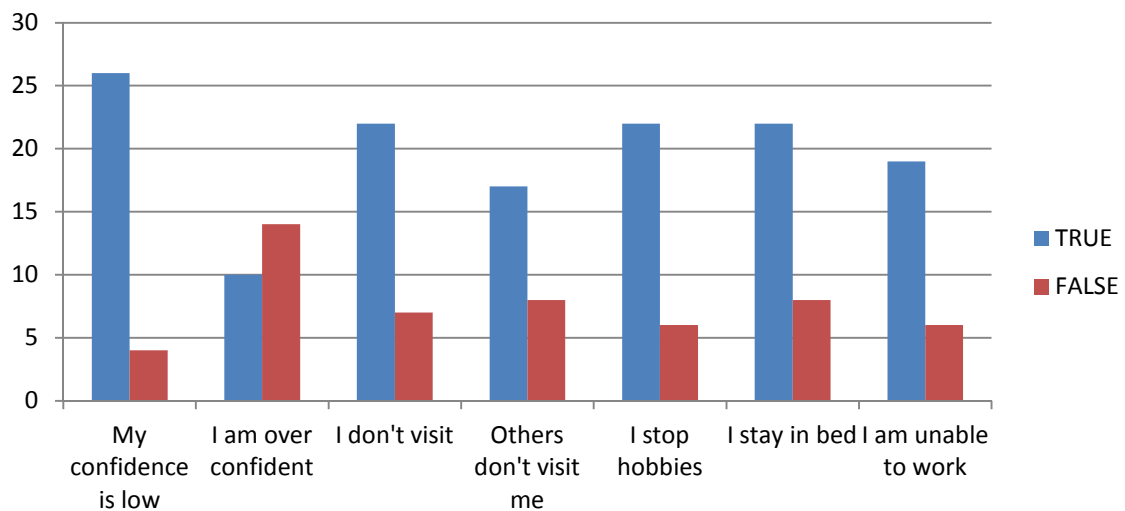
Q13. Does your care plan address your physical and wellbeing needs as well as your mental health needs?

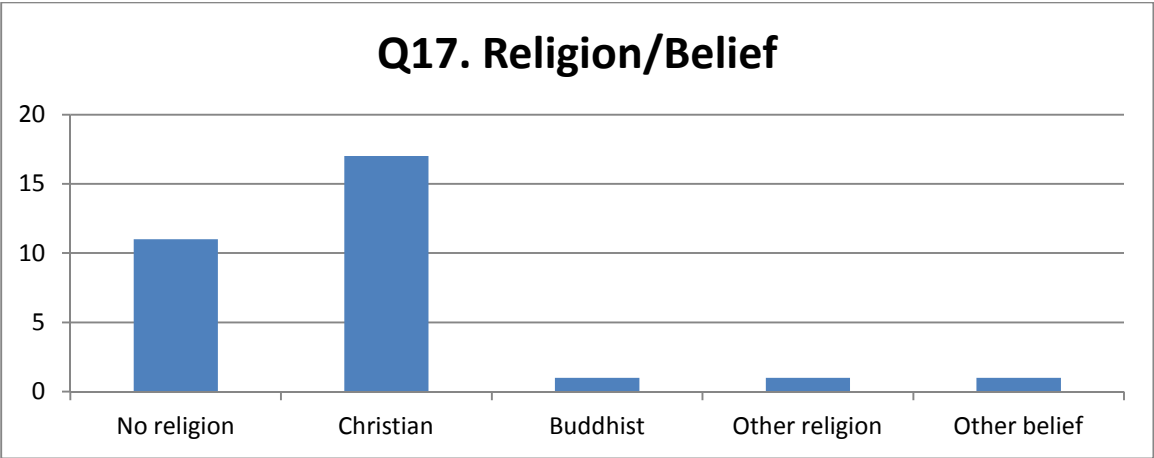
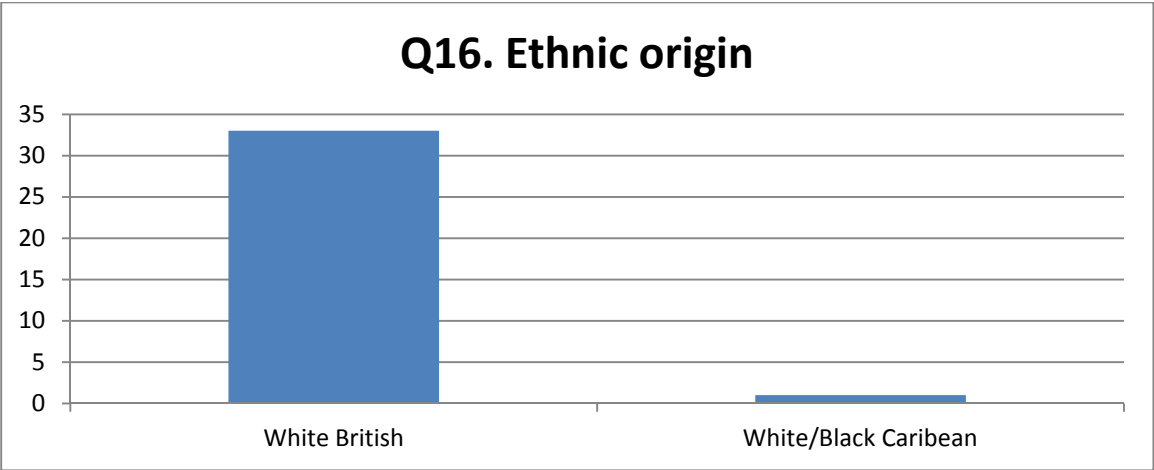


Q14. When I am mental unwell I ... :

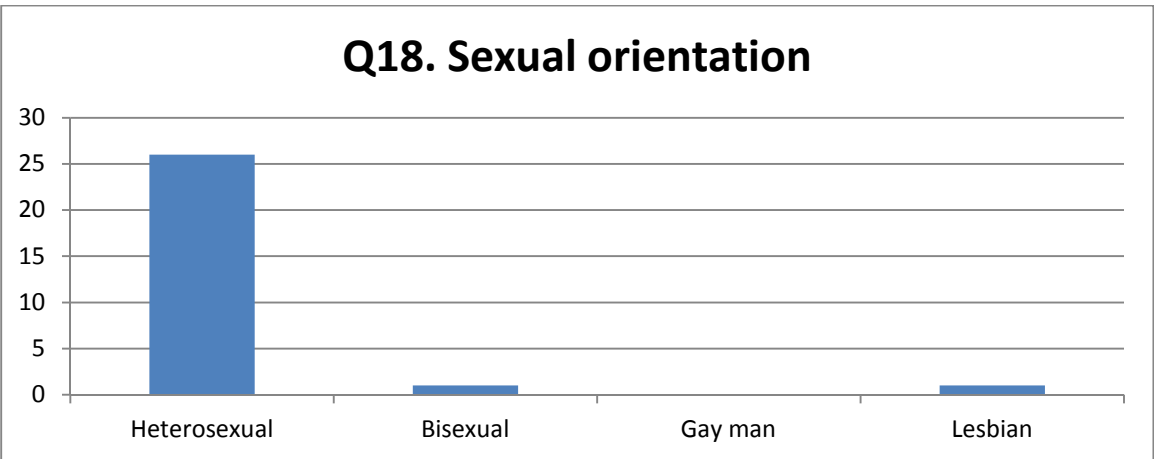


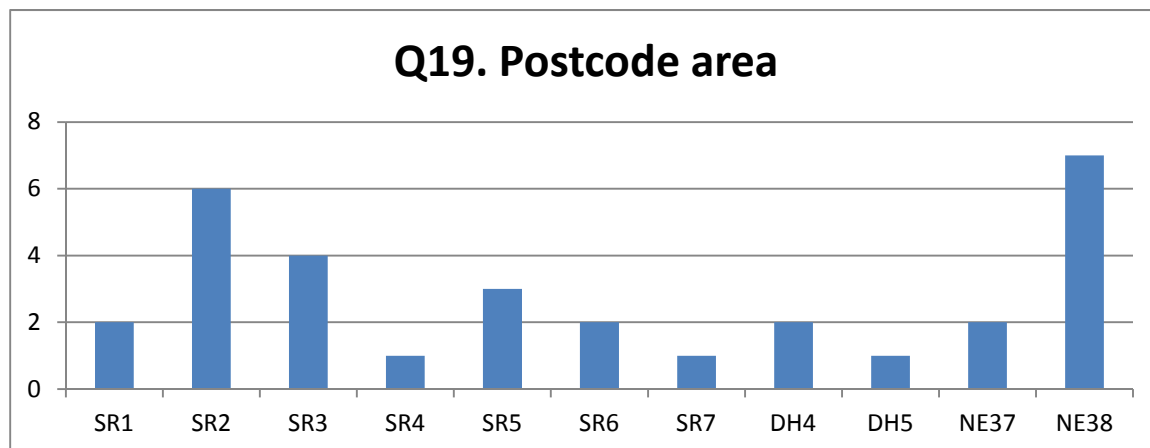
Q15. When I am mentally unwell:



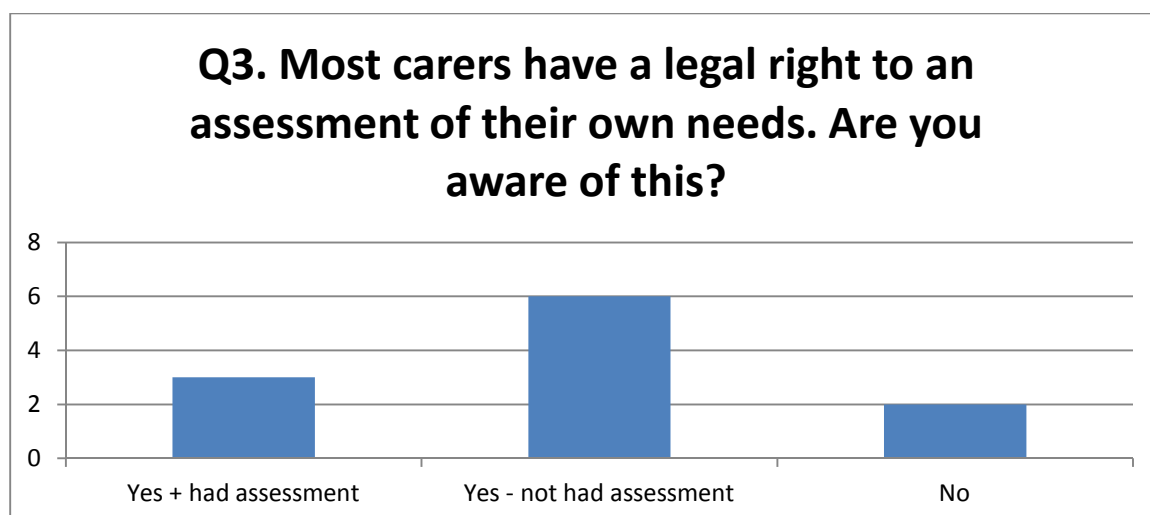
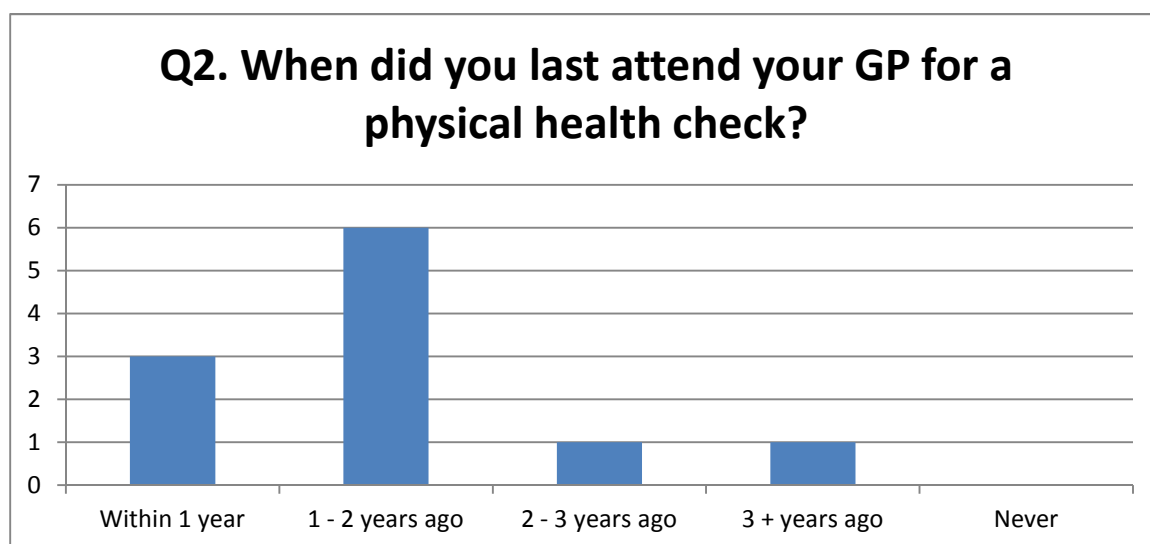
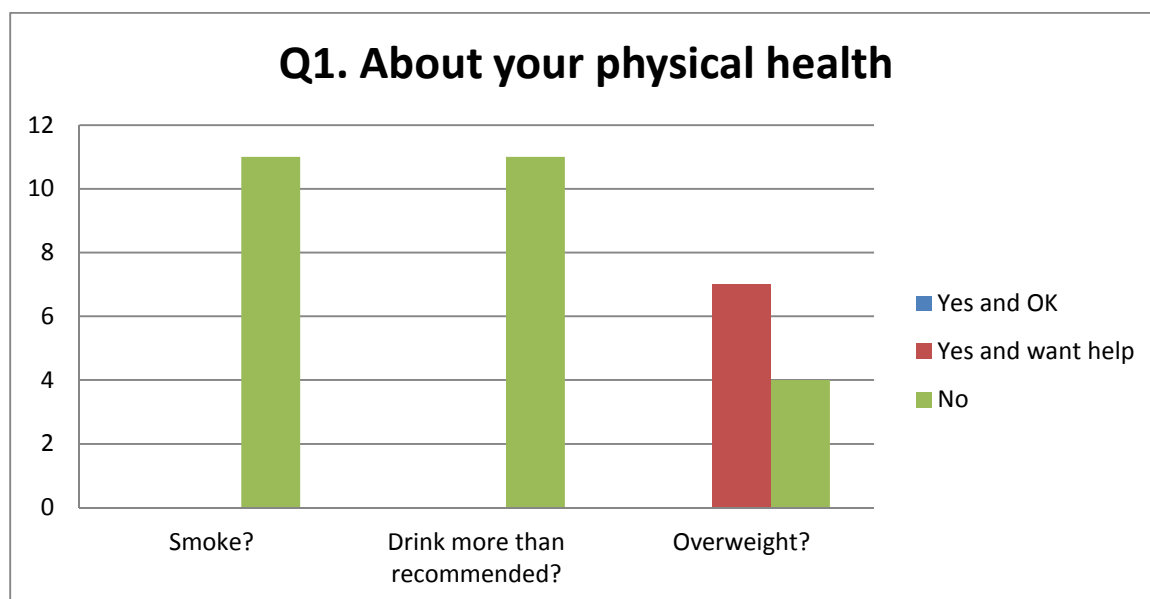


Other religion	Jedi Don't believe in God
Other belief	Born, live your life, say goodbye, gone!

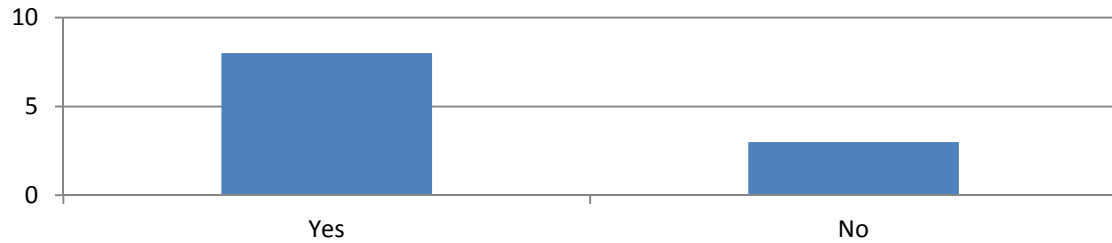




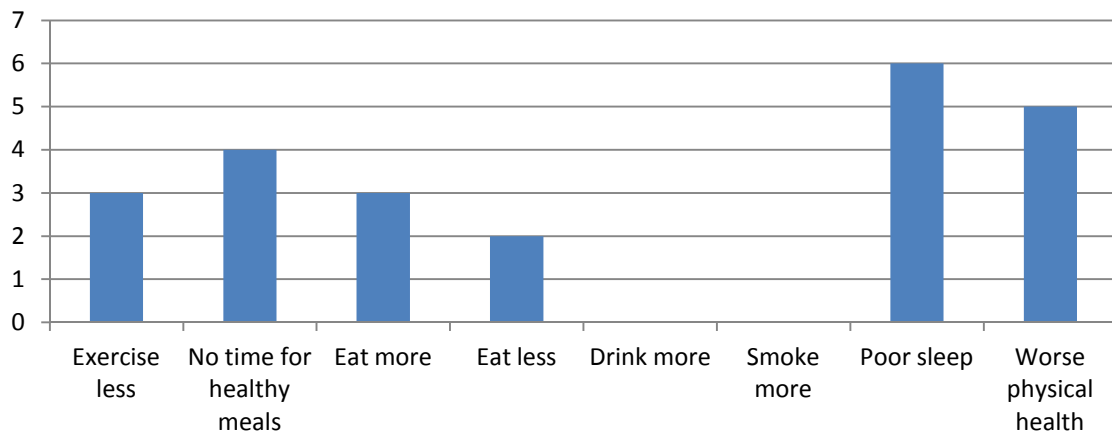
Carer Questionnaires - collated responses



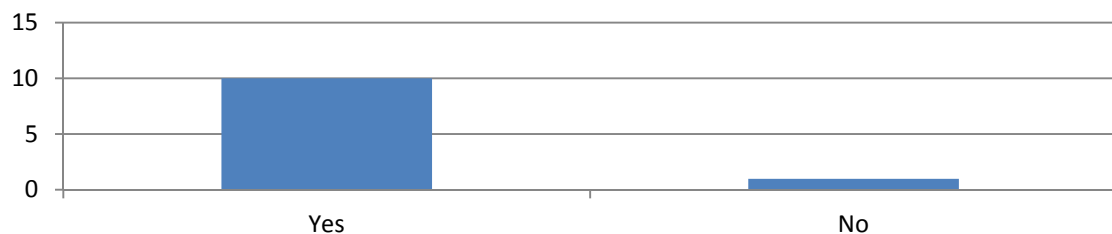
Q4. Do you feel your responsibilities/commitments as a carer impact on your physical health?



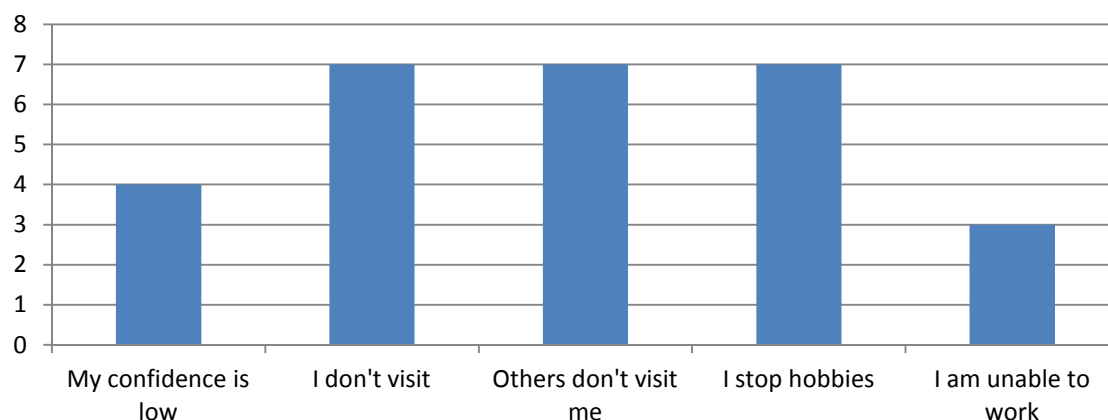
Q5. If yes, how?



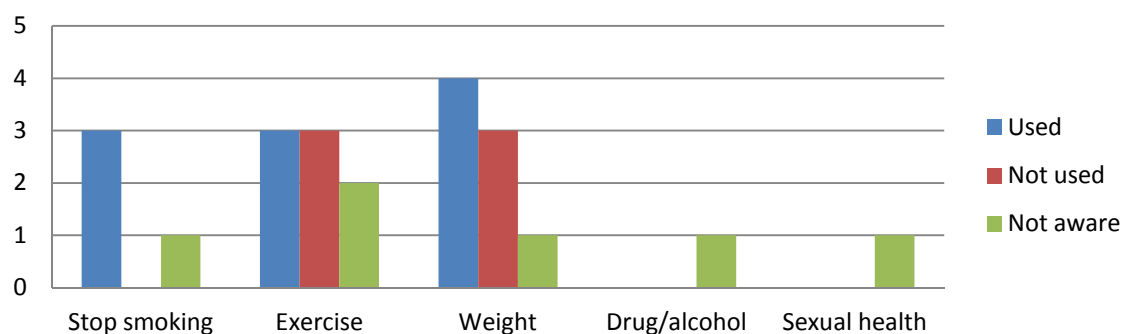
Q6. Do you feel your responsibilities/commitments as a carer impact on your emotional health and wellbeing?



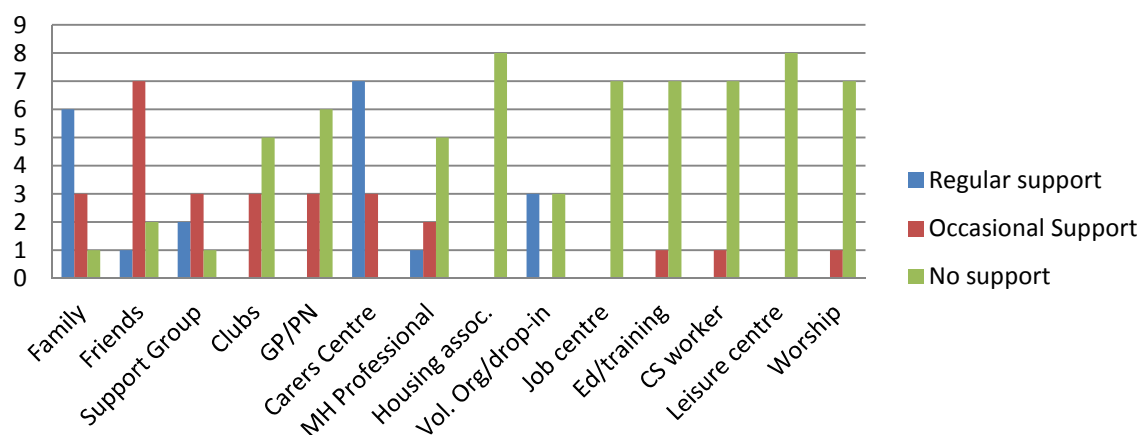
Q7. If yes, how?



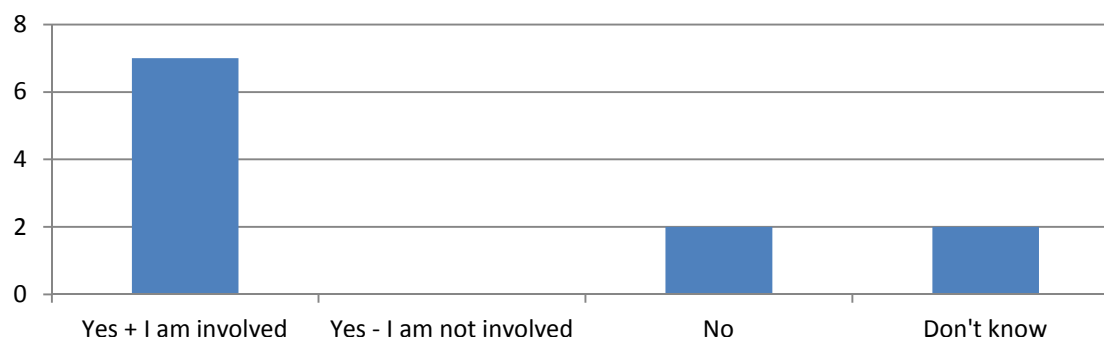
Q8. Please tell us if you have or are currently using, or have thought about using, any of the following lifestyle services:



Q9. Who do you have contact with/support from to help you keep physically & emotionally well and happy?



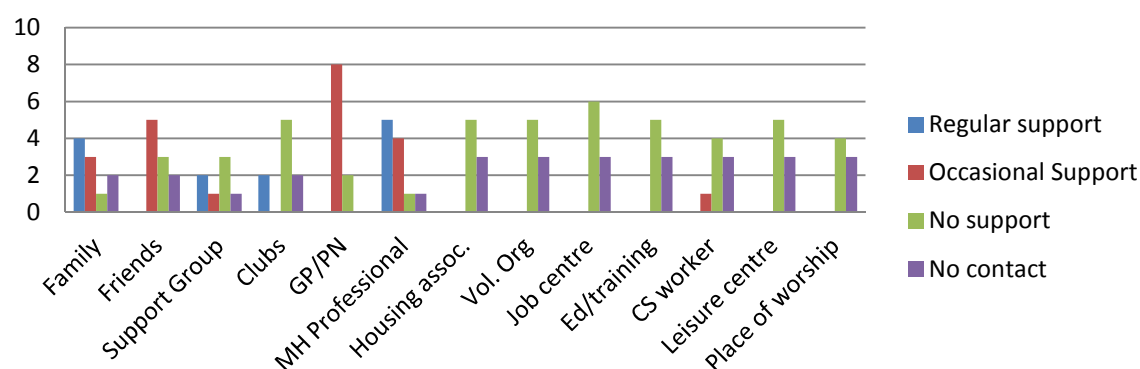
Q10. Does the person you care for receive their mental health care as part of the Care Programme Approach (CPA)?



Q11. Does the care plan address their physical and wellbeing needs as well as their mental health needs?

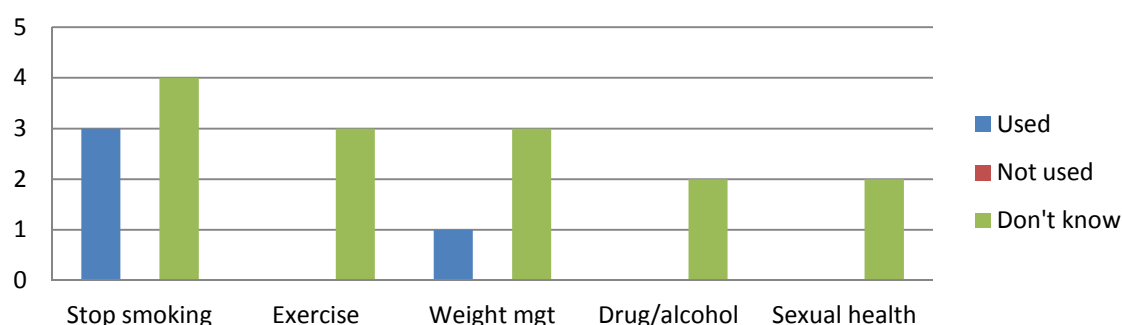


Q12. Apart from you as their carer, who does the person you care for have contact with/support from to help them keep physically and emotionally well?



Q12. Other:	Currently in hospital under Section 3 MHA
	Occasional support from pain management clinic

Q13. Please tell us if the person you care for has or is currently using, or has thought about using, any of the following lifestyle services:

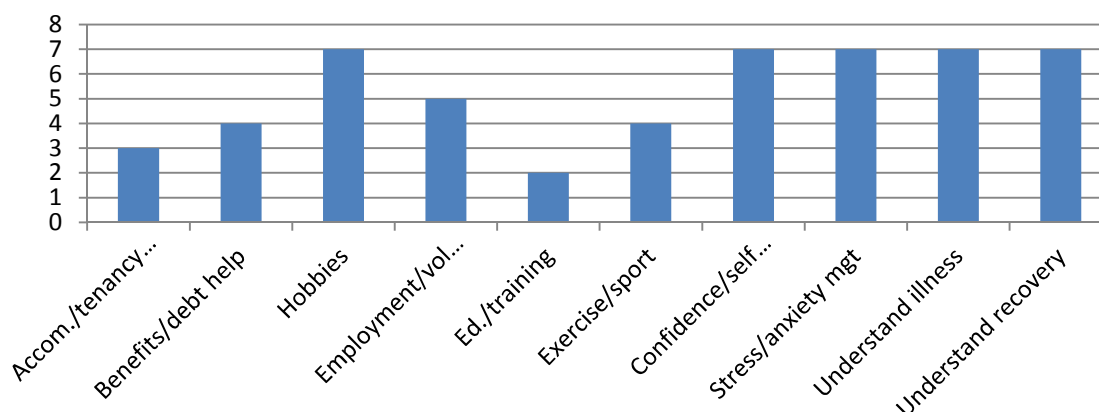


Q13 - cont:	
Other	Used hydro pool - Fulwell. 1x month (maximum)
	There should be a box to declare if patient has any intentions of using services, eg yes or no box

Q14. If the person you care for has thought about using a service but not used it, please tell us if you know why that is:

Service	Reason for not using
	No confidence in going out due to physical and mental health problems
Physiotherapy	Patient OK with this; NHS says 'reached plateau' and discontinued service
Mental health	Patients do know of most services but are reluctant to use them

Q15. What other support do you think would help the physical and emotional wellbeing of the person you care for?



Q16. If there was one thing that we could do to make it easier for the person you care for to live a healthier and happier lifestyle, what would it be?

Help to the art studio so they do not worry that it will close.

More access to a support worker to enable the person I care for to get out more.

It would be nice to both have a break together, anywhere simple and quiet, just to get away for a few days.

More people to give her time in the ward she is in - either staff or visitors - friends or professionals.

Combat stigma

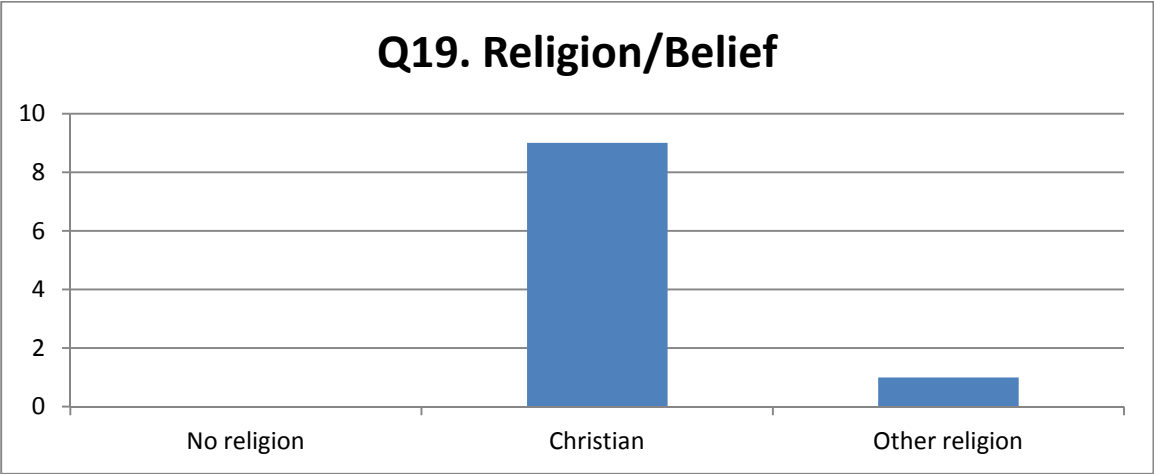
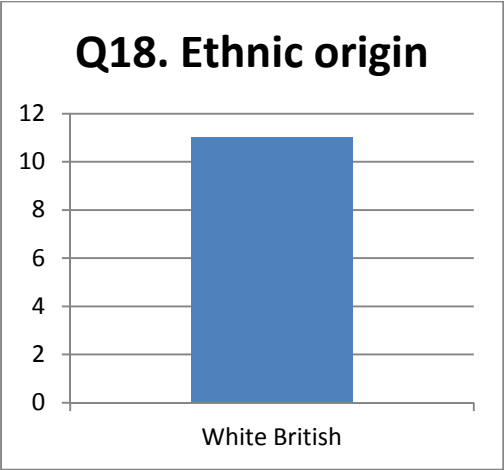
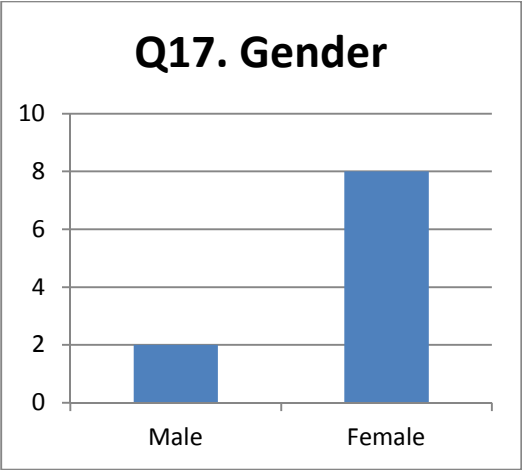
I believe the most important thing is that there should be consistency in the care that the cared for should receive. There should be more closer monitoring of cared for in the community.

Support on a more regular basis.

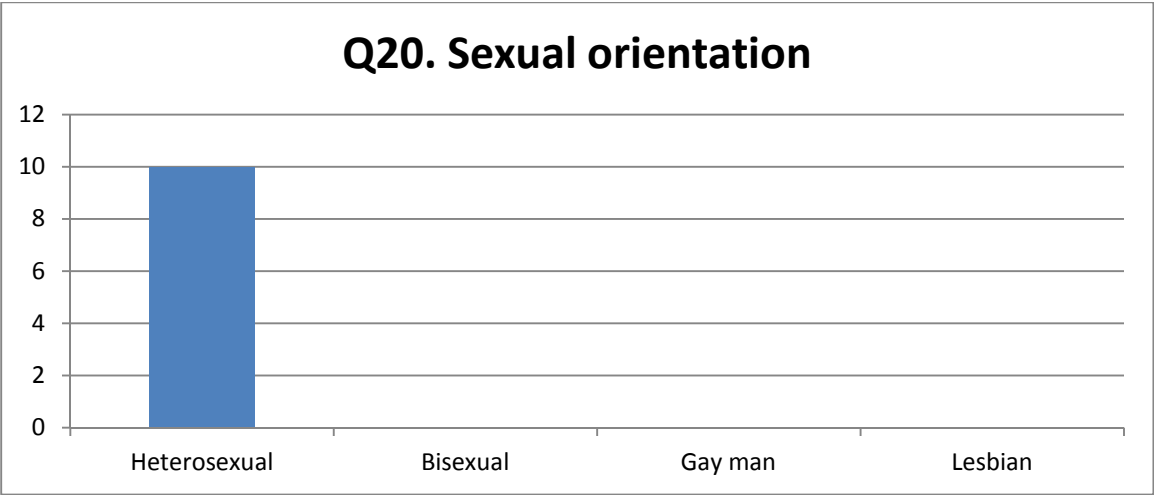
Give him plenty of attention and boost his confidence; give him 24 hrs daily care 7 days a week; fetch and carry for him; give in to his moods. He would be a happy bunny.

Be able to encourage the person I care for to join a support group, relevant to his condition (ME/CFS)

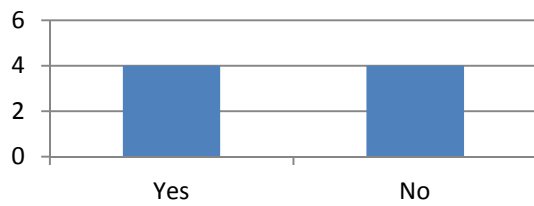
They need cognitive behavioural therapy (individual - 1:1 session



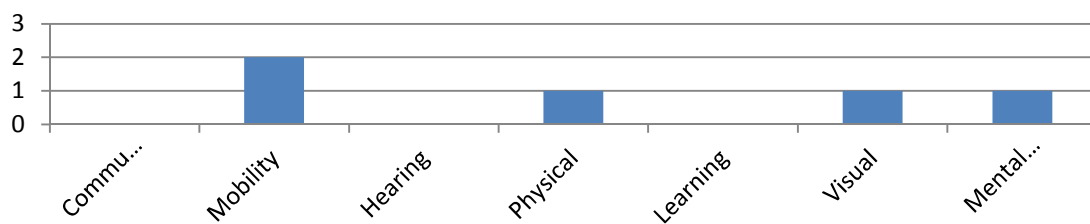
Q19 - Other religion	Methodist
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Q21. Do you consider yourself disabled?



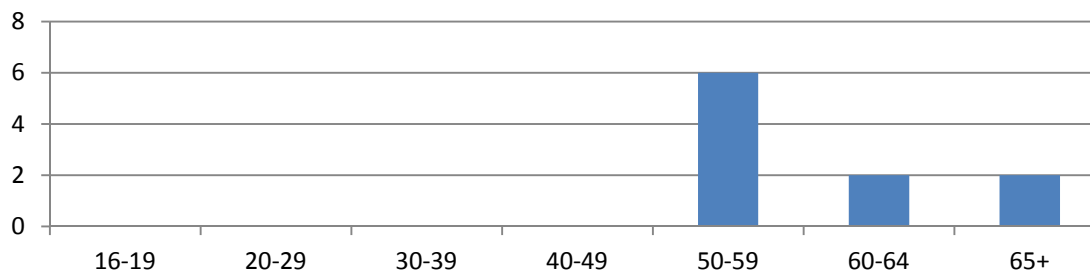
Q21a. If yes, how?



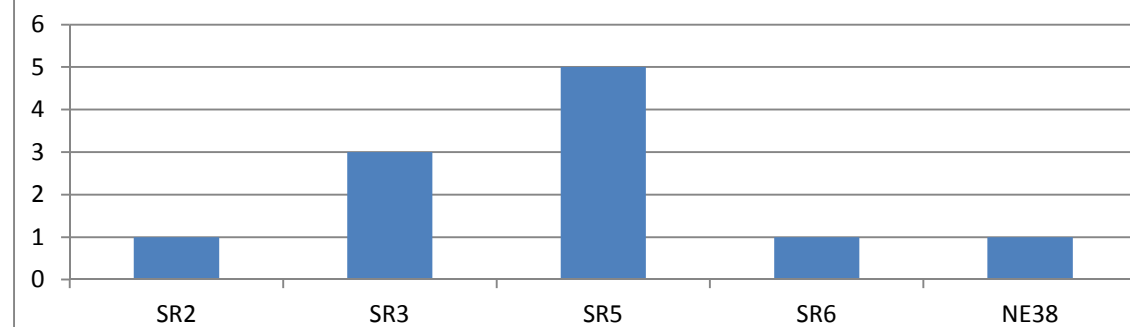
Q21a cont - Please give further details if you wish:

Type 2 diabetes + tinnitus + dizzy spells

Q22. Age



Q23. Postcode area



Interviews - collated responses

1. What do you think are the physical health and wellbeing needs of people with SMI?

- Not one I know is in good physical health
- Smoking, drinking - and use as a prop
- Living in long term poverty, no money for food
- Tend to be chaotic, day to day survival not planning for the next week for shopping etc
- Economically stuck
- Not addressing physical problems unless MH problems sorted and stable
- Smoking tends to be higher in people with SMI
- High use of alcohol and ?other substances
- Under-nourishment
- Late diagnosis (interesting link to Health Check)
- If you are schizophrenic you..
- Smoking - people with MH smoke half the tobacco in the country
- Sexual health - vulnerability
- - unhealthy choices
- Substance misuse
- Obesity - medication people are on
- Physical activity - discrimination
- - less confident about going out and doing things
- Emotional health - people who are not flourishing have a big impact on mental health
- Less likely to work so more likely to be in poverty
- Diet
- Don't get many SMI. Have to be stabilised
- First most popular re obesity, Second anxiety/depression (about 4 in 10) but high drop-out rate due to instability of illness.
- Tend to be overweight because of medication.
- Much greater
- Smoking greater, alcohol and drug misuse greater - they all come with a range of health issues.
- Social and cultural issues around smoking
- Lack of exercise
- Currently collect MH assessment GHQ12 - but it's not used, not asked for or used by commissioners - what do we do with someone if they score 23?
- Don't like group based stuff (when is it quiet - gym example)
- Tend to smoke more, exercise less.
- Smoking
- Weight issues
- Lack of activity - sedentary lifestyle
- EIP there is a real focus on medication and not gaining weight

- Community Services
- EIP South of Tyne
- Recovery Treatment Service - mostly around medication, clozeril etc
- Looking to move clinics
- Physical monitoring
- Maybe moving into GP practice
- About to develop medication management service
- More likely to have more smoking, less exercise
- Medication issues
- *Socio-economic drivers
- Very little drive to look at sexual health
- Can't deny the fact that there is a problem, they are not as physically healthy
- Historic focus on their MH as a barrier to looking at physical health
- Introduction of new wave of antipsychotics and weight gain issues
- Smoking cessation
- Medication makes life expectancy lower
- Weight gain - obesity
- Smoking - majority do - crutch for some people
- Shorter lives
- Poverty
- Bored and not getting...
- Patient in mind
- Psychotic with CMHT follow up. 20-50 yrs, smoking, obesity - diabetes
- consequences of anti psychotic meds
- We know it is important but in a 10 min consultation it will come last.
- More focus on prodromal side effects, ie. Clozaril
- Would refer either to NTW or mainstream providers
- What makes them different is their illness which takes a lot of time and energy so the focus.
- Impact of medication - weight, motivation, just accepted
- Over prescription of beta-blockers and tranquillisers for anxiety and 'to take the edge off'.
- Reflection of a deprived area, not seen as an issue. People approach it from completely different question. All aspects of their wellbeing. LA view is that GP or secondary care responsibility to pick it up. Physical health not high on LA priority list. They use FACs.
- DD 60% of alcohol users had dual diagnosis.
- Same as everyone else.
- What percentage of people with SMI smoke/overweight etc. Exercise services.
- Diet and exercise slips when people with depression have low mood
- Depression stops people going out
- Medication - obesity - attributable to mental illness
- Can people access services when they are unwell?
- There is currently a weight management/12 week plan at Headlight

2. What do you think are the barriers for people with SMI accessing services to address their physical and wellbeing needs?

- Barriers - the reaction of the others to them when unwell
- Stigma to deal with
- Got other things on their mind than stopping
- Benefit reforms are a nightmare
- Lot of agencies are bums on seats
- Funding 3rd sector is a big issue
- Physical health is often left until last.
- How we have silo'd things up and paid for things, ie exercise was tackled via obesity.
- Workforce issues in dealing with SMI - competencies in advisors.
- Do we take the service to them or make the service flexible enough for them to come.
- Discrimination
 - SMI can be more obvious
 - exists within lifestyle services themselves
- Really how accessible? tend to be geared around people who can access them.
- Do they have the confidence to be able to access services.
- Drop-out due to lack of support (family or service)
- If people are working it can be difficult.
- No more or less than general group - time, money, childcare
- Advisors are frightened of people with mental health conditions.
- Way they have been commissioned people with but not a specific group they are contracted to do, lack of skills but also not helpful to hit their targets.
- People with diagnosis of mental health issues are high DNAs
- Costs (travel etc) costs of sessions
- Not up on a morning, lack of life pattern/sleep pattern, transport issues
- drop-out rates are high
- We have set sessions, not always accessible
- Motivation and engagement
- Awareness
- Need a lot of support to get to and keep it up
- Being patronised by services
- Assumption that they are separate and not their issue
- *Acceptance of mental health services that people will gain weight
- What about the legal side
- Staff apathy
- Primary care staff - there is a certain amount of fear
- Are people with SMI accessing them - no
- Do they know they exist
- Are they being treated differently, attitudes and stigma around stopping people joining
- GPs - getting fed up being asked to do complex physical health checks - now want paying for it (there is in current QOF)
- Stigma, would never think of going to a gym
- Only focus on mental health and not physical health
- Go there for smoking, somewhere else for obesity
- Integrating into community life
- Implicit
- Getting people to come through the door

- Invisible barrier of primary focus on MH disorder, perception of lack of interest in change
- Perceived as this is going to be tough, don't want to upset the apple cart
- Annual check, who is looking after it - psychiatry/primary care
- Because caseloads are huge if you're doing alright you get left.
- Practice staff get freaked by mental health, even though focus should be bloods etc - no training and lots of misconceptions.
- Are people with SMI getting the annual health check?
- Secondary care teams under immense stress.
- Losing a lot of knowledge and skills through compartmentalising, o skill mix. Cultural barriers, split health and social care. We don't know what is out there and how to access it. It's not high on the patients list of priorities. Resources are quite scarce in this borough.
- Access (even physical access) ie. transport, confidence, finance. Making that first step, is there enough info to let people know what is there? Main stream or specialist service.
- (Can medication be used by people with MH)
- Family/social situation.
- Communication with a professional.
- Building their capacity to recognise their own physical health needs - how do you do that?
- A 12 week weight management plan doesn't suit people if they get unwell - same with smoking.
- Exercise on referral - if they drop out they can't get back in again.
- Clinicians don't always understand the preventative side.
- Never get asked about individual Health Plan outcomes - just measured on caseload and assessment numbers, number of referrals, number of people complete, number of 5-a-day, number of 30 minutes exercise.

3. What kind of changes do you think need to be made to encourage people with SMI to access lifestyle services?

- Physical health problems tend to be ignored by health professionals
- Can't get past mental health
- People who attend use social meetings but not cooking lessons or exercise classes
- Need to have really skilled tutors to deal with people with SMI
- Even if needs are articulated they are not believed
- Incorporating different approaches to things
- Something about the concept of how physical health affects mental health - training for service users and others.
- Wellness service - good way to think about it.
- Take smoking cessation services into mental health instead of how will GPs address this (GP mental health leads)
- Link to NHS Health Check
- Could be tweaked
- Speaking to local people, don't get it right from a service perspective.
- Should we be making current services accessible or do we want specialist services.
- Develop a known pathway, spend time on Bede and get faces known then support people to come from staff there.
- Some need ongoing support after

- Group interventions rather than 1-1
- Going to existing mental health groups - health trainers?
- Training for lifestyle service providers on mental health
- Any service can train up and deliver smoking cessation.
- Sunderland and Washington Mind.
- Contract - insurance
- - one member of staff trained up to be a smoking advisor can generate significant income, now have business model for getting organisations signed up. Contract changes in £15 for each person who sets a stop date, £35 for everyone who quits at 4 wks & ?another £41 if still quit in 12 weeks.
- Are we targeting services at these groups?
- Are we communicating them well?
- Reinforcing the issue with commissioners of lifestyle services
- Use GHQ12 for referral on
- Point of referral - people often don't know what they have been referred to and why
- More 1-1 time with people
- More training for staff on mental health and it's relation to exercise
- Storyboard
- They did some stuff with Washington Mind
- Who do people with SMI have access to/real practical advice?
- We run a football groups
- Based in GP practices, take services out to patient (their own physical health services she is talking about it)
- Improve relationships with GPs
- Something built into paperwork to highlight and record what interventions
- Education and attitude change
- Accessible
- Sunderland IAPT delivered by MH Trust so closer links with Physical Treatment Service. Both primary care and IAPT.
- Good Practice Compendium.
- Do more to encourage people to attend
- There has been some shifts by inclusion papers
- Physical trainers in CMHTs
- STR workers - on Teesside a while ago sent them on health trainers course
- Using CQUINS in contracts - physical health checks - NTW
- There will be some outcomes re physical health needs in new CPPP
- Put it all in one place
- Need one to one support - go to health trainer
- Need to try and mainstream people not put them in boxes
- Want to move to integrated teams, smoking, obesity etc
- Tackle discrimination
- Keep holding events and expect people to come to use, reviewing health trainers
- We need to embed emotional health and wellbeing fully integrated into physical health services
- Need to be more proactive with this client group, not aware of any special measures as GPs; local enhanced services.
- written in CQUIN scheme for trust to encourage people to attend health checks

- A clearer line
- Has capacity to employ 1 session a week (2 people) to do the work.
- GP contacts interested in MH/LD/Dementia in South Tyneside.
- Change commissioning targets to make wellbeing a target but not on top of everything else.
- Physical health is not part of clustering (not a key clustering criteria) so if this is how the money comes then it will never be a priority.
- Part of discharge planning for primary care mental health teams.
- Use STR workers to support people to access services or do it themselves.
- Connect the STR workers directly with the lifestyle providers.
- Green gym.
- Some kind of networking, communication opportunity might help.
- No formal comms system in statutory services - needs to be a collective approach Make it a target again, make it a priority.
- Make it front page of assessment and part of care plan to treat each physical health problem.
- If they are in touch with services we need to skill up the workforce.
- Improved marketing and comms; what is currently done is it in the right places?
- Learning disability - lack of resources, lack of knowledge and skills.
- Training to do cholesterol checks.
- Health trainers are outreach.
- Lower smoking targets to less cigarettes rather than complete stopping.
- Measuring how many people start and finish, so anyone who drops out is seen as a failure.
- Services need to be more flexible in terms of outcomes.
- Services need to go to people.
- Confusion re services, ie active bus, health trainers, health champions.
- Over 40's checks; if there is a need they should be referred in.

North of England Mental Health Development Unit

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