User Focused Monitoring
By service users *for* service users

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User Views on

First Interventions in Psychosis

To support the development of the

Early Intervention in Psychosis Team

November 2003

MaryFrances**Trust**

innovation in mental health through involvement

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Acknowledgement

Acknowledgement

The Mary Frances Trust User Focused Monitoring Team would like to thank those involved in the development of the Surrey Oaklands Trust Early Intervention in Psychosis Team for the support they have shown this project.

Due to Kathy Taylors' foresight and Jo Lynchs' ongoing partnership working with us, we have been able to support development of the new Early Intervention In Psychosis (EIIP) team. This has been a really effective partnership and has been documented in the Sainsbury Centre Guide to developing EIIP Teams.

'A good example of user involvement has been the development of the Early Intervention Team at Surrey Oaklands Trust. The EI project here has worked in partnership with the Mary Frances Trust (MFT), which is a small charity that seeks innovative ways to involve service users across the whole spectrum of service planning, development, delivery and evaluation. The MFT recognise that different service users want to be involved in different ways and at different stages in the process. They have broken tasks down into many components within frameworks that ensure consistency and continuity yet enables many different individuals to participate.

Service users were active members of the Early Intervention steering group. Additional meetings were held for service users, to update and explore issues on latest developments both locally and nationally, to enable active participation and also to widen the number of users involved (without requiring everyone to attend every meeting). The service operational policy, service philosophy and objectives (etc.) were written in partnership through the steering group, ensuring that the finished document and service development proposals were accessible to service users.

A significant development resulting from this involvement process has been the 'User Focused Monitoring framework' that allows service users to hear first hand from other service users about their experiences of first contact with mental health services, in order to further inform the development of the service. Supported by Surrey University, initial data is now being analysed and an ongoing monitoring and evaluation project, using the same principles of multiple user involvement, has been established'

However none of this would have been possible without the dedication of the team itself, congratulations to everyone who took part in this brilliant piece of work.

Jackie – Co-ordinator

1. Introduction

This is the final report from The Mary Frances Trust User Focused Monitoring (UFM) Team. Reporting mental health service users' experiences and recommendations to inform the development of a new Early Intervention in Psychosis Team within Surrey Oaklands Trust.

2.   Method

The UFM consisted of ten service users who:
- Developed the questionnaire used to record information
- Collated data
- Provided administrative support
- Analysed recorded data

A project co-ordinator and an external evaluator supported the process.

A total of seventeen service users were interviewed for the project. The method emphasised data quality rather than data quantity. The report draws on experienced service users' good and bad experiences with previous and existing mental health services. It puts forward their views as to how future services can be improved and draws on the opinions of people who have experienced first episode psychosis.

The UFM Team has endeavoured to engage in a collaborative reflective effort to examine the issues and provide a generalised understanding to consider individual circumstances.

3.   Findings

Service users identified three key principles to describe quality in mental health care:

1.   Holism *(or wholism, 2. Med. The treating of the whole person including mental and social factors rather than just the symptoms of a disease)*
2.   Respect
3.   Sincerity

The Early Intervention in Psychosis Team should consider these principles as central to their team development process.

3.1 Holism

- The illness perspective must be integrated into a wider perspective of the life of the service user.
- The service user is a person with a background that influences his or her mental health problems.
- The social and physical environment of the service user is crucial for the prospect of recovery – i.e. (money, housing, employment, education and colleagues).
- The family and close friends have important roles to support the recovery process.
- The strengths (and not the weaknesses) of the service user must be the focus of recovery.

3.2 Respect

- The service user is a person and has to be treated as an equal by those working for Mental Health Services.
- The service user should be given clear and detailed information.
- The effects and possible side effects of psychotropic medication have to be explained clearly.
- The service user ought to be involved in discussing treatment options.
- The service user's concerns should be addressed in a clear and informative way.
- The service user's plans and wishes for the future should be considered in the overall plan for treatment and recovery.

3.3 Sincerity

- EIIP Team members should demonstrate honesty when dealing with the service user.
- EIIP Team members have to show genuine care for the service user.
- Continuity of care through a long-term key worker facilitates a supportive personal contact for the service user.

4.   Further Initial Recommendations

These key three principles also reflect the need for this type of approach in all Mental Health Services. More specific recommendations regarding early intervention in psychosis are summarised below:

4.1 Medication

- Use low dosage medication wherever possible
- Inform service user about effects and possible side effects.
- Respect the service user's concerns about taking medication.

4.2 Psychiatric wards

- Try wherever possible to avoid hospitalisation.
- Consider that the service user is very sensitive and needs good support.

4.3 Psychotic experiences

- Provide service users with an opportunity to talk about their experiences in a supportive environment.

5.   Statement of Value and Intentions

❑   The Mary Frances Trust User Focused Monitoring team believes that any project it undertakes will be User-led, with sufficient support and encouragement from all individuals and organisations involved.

❑   The team will ensure that all information and suitable training is available in a way that is easily understood and explained.

❑   The team will ensure that any project will be safe for all involved, including, but not limited to, areas such as privacy and confidentiality, health and safety and Human Rights. The team will ensure that any feedback given is respected and considered appropriately and that confidentiality is assured.

❑   All complaints will be dealt with appropriately in line with the Mary Frances Trust complaints procedure.

❑   The team believes in operating in a way that respects equality, choice and the diversity of the individual including ethnicity, gender, age and religion.

❑   We respect individual choice in involvement, it is of a voluntary nature and every individual has the right to change his or her mind. Each team member will be aware of their own and other member's responsibilities, commitments and expectations.

❑   All work undertaken and decisions made will be co-operative. All those involved will be listened to; the team recognises that projects may need to change as a result.

❑   We will carry out each project in a caring, dignified and non-judgemental way with accuracy and understanding.

Signed

The Mary Frances Trust User Focused Monitoring Team

6. Aims and Objectives

6.1 Aim

To interview and obtain the opinions of Mental Health Service Users concerning first experiences with Mental Health Services.

6.2 Objectives

- Teams of mental health service users supported by a User Involvement Worker will interview as many service users as possible in the permitted time scale.

- Opinions of service users will be obtained through structured interviews conducted by trained teams.

- The interviews will be written up in the exact wording used by those interviewed.

- A report will be prepared identifying the main issues and will be supported by examples of views obtained.

7. Process

- The Team made four initial visits to ensure that service users and the staff supporting them were aware of the project and the processes involved.

- The Co-ordinator (of the Early Intervention Project Surrey Oaklands Trust, Early Intervention in Psychosis Project) advised staff of eight sites for this project.

- Dedicated space and time was allocated for interviews.

- The interviewing teams conducted the interviews on follow-up sessions or as individual interviews.

- The interviews were completed over a four-week period in August 2003.

- A key observation was the enthusiasm and passion of the service users to be able to use their to influence the development of future services experiences.

- The Team Co-ordinator de-briefed interviewing teams.

- The Team was supported and monitored through the whole process by John Larsen of Surrey University - external evaluator. John ensured appropriate methods were used, supported interviewers and those interviewed. John Larsen will support this document with a process report.

- The Administration Team typed all the interviews word for word.

- In order to ensure that themes arising from this exercise reflected the opinions of those interviewed, individuals were met for a third time where possible. The process was discussed and further information collected.
- Emerging themes will be discussed by the team with John Larsen and will be collated into a report, which will then be printed and distributed.

8. Roles Within The UFM Team

To understand the value of User Focused Monitoring in producing this report, it may be helpful to understand the roles within the team:

8.1   **An external evaluator** – John Larsen was chosen to ensure our process was transparent and to assist in learning from our experiences. He also aided in ensuring our processes were ethically correct and had appropriate support mechanisms in place.

8.2   **Interviewers** - teams of 2 service users who have received training to interview other service users regarding the services they receive. They were part of the team that designed the questionnaire and the prompt questions.

8.3. **Data collators** - these team members wrote up word for word the information the interviewers returned with. Some service users were not available or did not wish to be interviewed and were offered the option to complete the questionnaire and post it to us. These were also typed up.

8.4. **Administration Support** - these team members ensured paper was ordered, questionnaires printed and were instrumental in the final printing of the document.

8.5. **The Project Co-ordinator**, whose job was to ensure a smooth process and support any team member or service user as required. This included provision of transport for the interviewers, supporting interviews if required and de-brief of interviewers afterwards. This role was vital to support the interviewers, the interviewees and other service users who observed but were wary of the process.

9. Findings

9.1 Interviewees

Interviewees indicated their age group, as seen in Figure 1. One was under the age of 30, the largest group was between 35 and 45 years old and approximately a third were older than 45 years.

9.2 Age of interviewees (graph)

Figure 1: Age of respondents
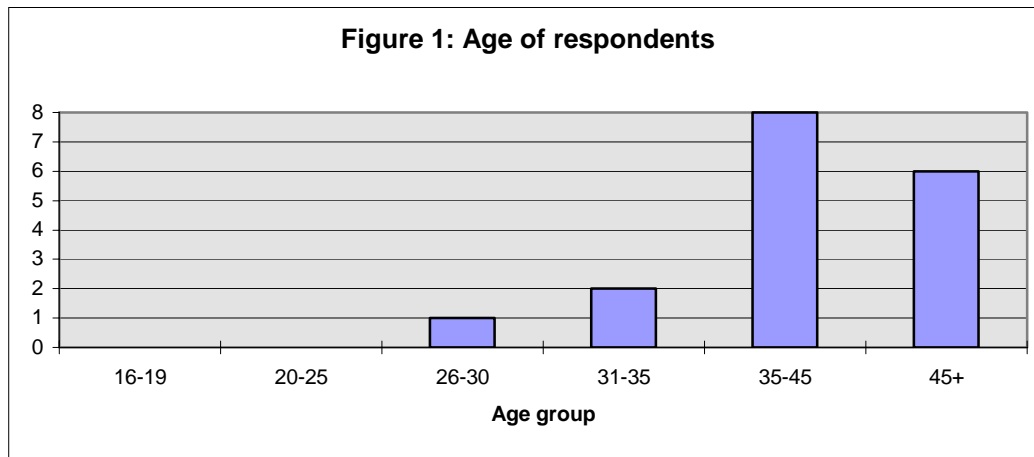
9.3 Gender (graph)

As seen in Figure 2 the majority of the respondents were male.
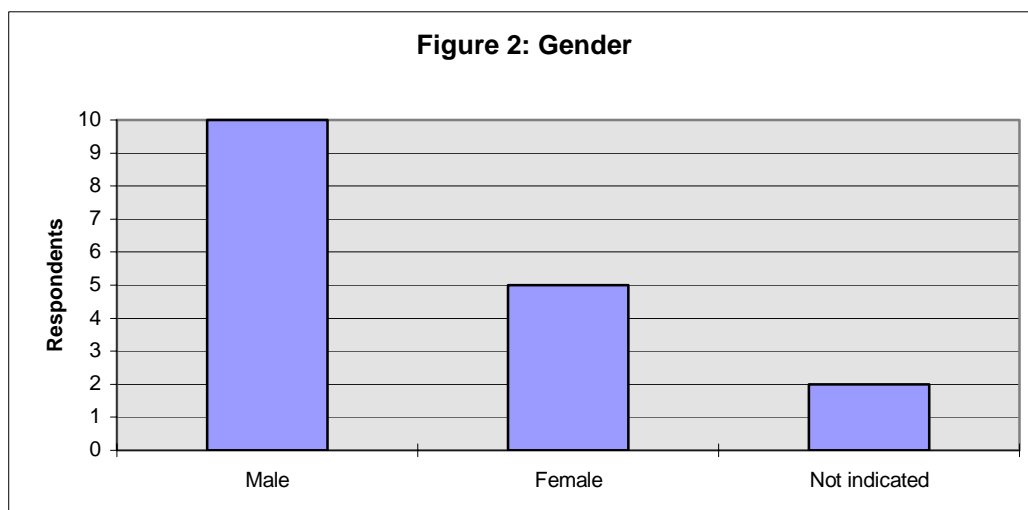

Figure 2: Gender

9.4 <u>Ethnicity</u>

The interviewees described their ethnicity in various ways:
- ❑ 'White British' (n=4),
- ❑ 'White English' (n=3),
- ❑ 'White Welsh' (n=1),
- ❑ 'British' (n=4)
- ❑ 'English' (n=2).
- ❑ Three respondents chose not to answer this question.

9.5 <u>Marital Status (graph)</u>

The largest group among the respondents was divorced, about a third or the respondents were single and less than one in five were married. Four indicated that they had children, two of which were married.

Figure 3: Marital status
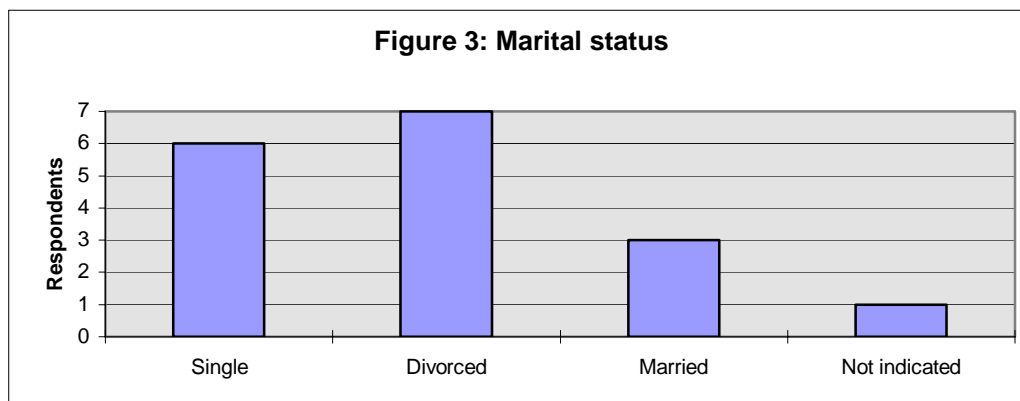
9.6 <u>Life Circumstances</u>

An indication of life stresses before first contact with mental health services

The respondents pointed to difficult life circumstances having an important role in developing or intensifying their mental health problems. A few extracts from the questionnaires illustrate the complexity of the difficulties they were struggling with:

- ▪ 'Ex-wife and her family were giving a hard time and I had no help from my family. I needed accommodation, a job, and I had financial problems.'

- 'Bullied at school from 14, work – didn't like the people I was working with.'

- 'I was in the middle of a degree, so I was pressurised – and at that age (22) had little experience of coping (SURVIVAL!!). I got depressed deeply about everything. And had increasing paranoia. I knew it wasn't right so I had some counselling – but I felt I was not taken seriously. I also had loads of personal problems (baggage). In short, my "problems" led to emotional exhaustion and a full-scale breakdown in early 1989. Other problems didn't help either.'

- 'Agoraphobia, pressure on marriage, unemployment, coping with children, alcohol, anxiety & depression.'

- 'I became homeless. Isolation.'

One respondent had been affected by the public tragedy publicised through the media:

- 'The news of the death of John Kennedy made me feel threatened and vulnerable.'

The UFM Team identified seven common 'key' issues mentioned by the respondents as factors in the environment or their personal life circumstances which influenced their mental health at that time:

1. *Difficulties with education or job*
2. *Money problems*
3. *Pressure from family*
4. *Housing problems*
5. *Problems with alcohol or drugs*
6. *Personal trauma*
7. *Public tragedy (communicated through mass media)*

Figure 4 illustrates how many times each of these issues were mentioned

Table 4: Issues that affected mental health
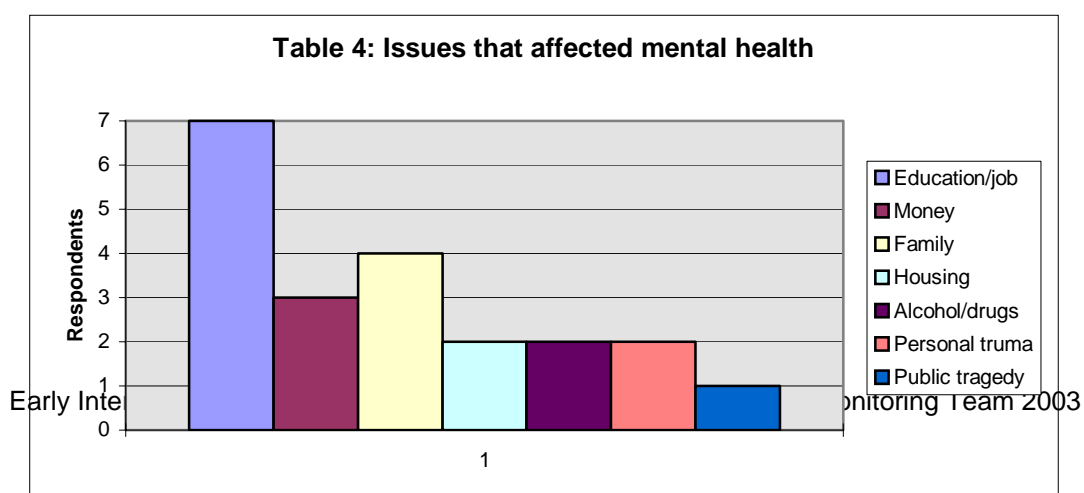
by the respondents.

9.7 First Contact
First getting in contact with mental health services

The interviewees were on average 28.2 years old when they first had contact with mental health services. Figure 5 below illustrates the individual responses.

Figure 5: First contact with mental health services

This finding was discussed in the UFM Team, it was suggested that the relative high age might reflect that some respondents have different views on what constitutes 'mental health services'. While some possibly have taken it to mean when they first suffered severe mental health problem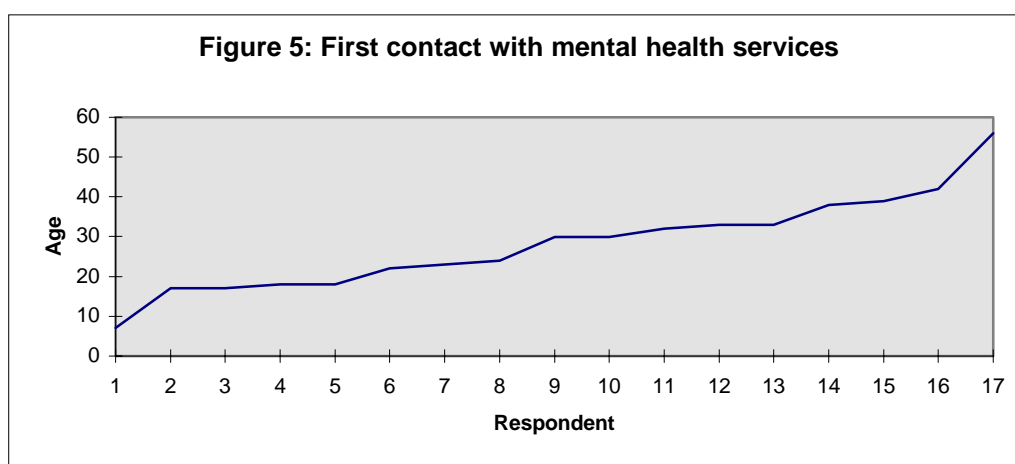s, others could have indicated when they first saw a psychiatrist, and others again could have put down the time when they first had been admitted to a psychiatric ward. In some of these cases, they might have seen their GP about their mental health problems before going to hospital. Therefore, these responses may not give a precise and actual age of the time they first reported having mental health problems to a health professional.

Among the respondents a majority of ten (59%) were aware that they needed help before their first contact with mental health services while seven (41%) indicated that that they were not aware that they needed help.

The respondents were asked who first made that contact to mental health services, as shown in Figure 6. The findings show a mixed picture of self-referral, family, health and social services and police. One had contacted

the police, and it can therefore be argued that an element of self-referral was involved.

Figure 6: Who made the first contact to mental health services
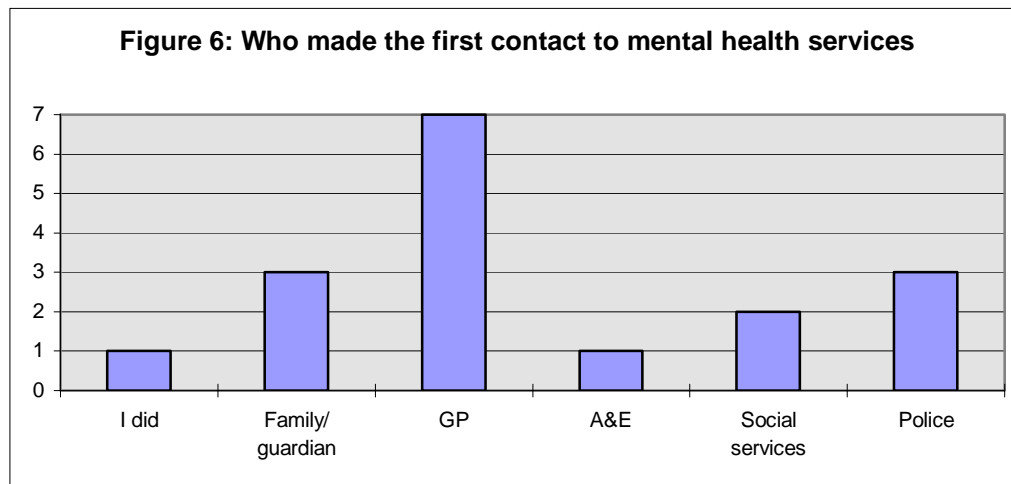
The UFM Team agreed that self-referral must also be said to be the case when respondents indicate their first contact was made by their GP or through A&E. This interpretation of the data means that about half of the respondents, directly or indirectly, came in contact with mental health services through self-referral.

Rather than using the legal definitions of force and sectioning it is relevant to ask whether the respondents were willing or unwilling to receive mental health treatment at the point of their first contact. About a third (n=6) of the respondents indicated that they were unwilling. In the cases of three of these it was a member of their family or a guardian who had made the first contact. Three other persons who were unwilling had got in contact with mental health services through the GP (n=2) or the police (n=1).

About a third (n=6) responded that they had changed their mind about being willing or unwilling to engage with mental health services. Notably, three of these changed their mind from being unwilling to being willing.

10. Mental health treatment and support

When looking back first contact experiences with mental health services responses where mixed as to whether it was seen as positive or negative event, as illustrated in Figure 7 below.

Figure 7: Assessment of contact with mental health services
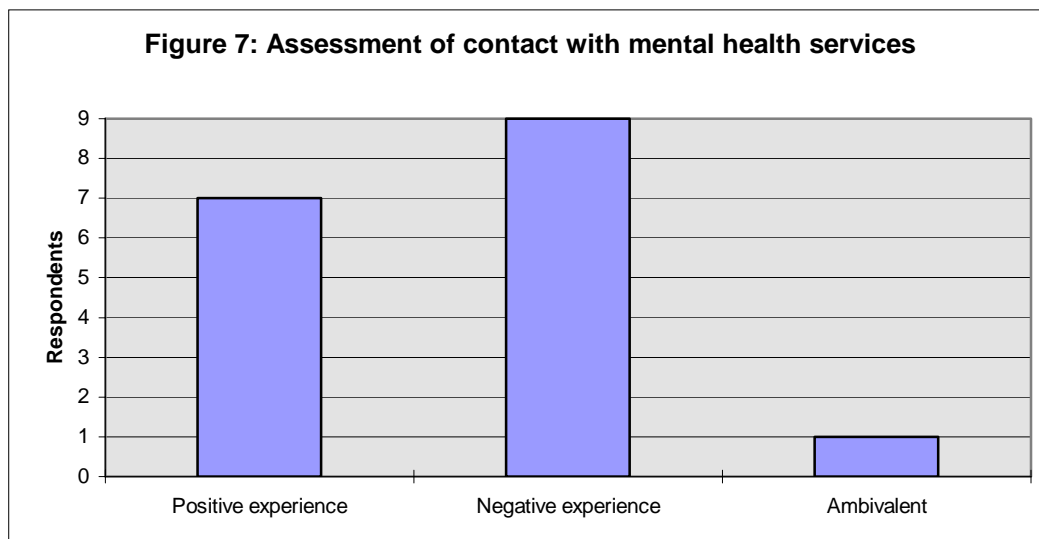
Discussion within the UFM Team revealed that this overall ambivalence could be explained by the complexity of the situation when first getting in contact with the mental health services. The same person can have both negative and positive experiences. The negative experiences can reflect the chaos in the life of the person at the time of the active psychosis as well as the general uncertainty they experienced when encountering the mental health service. Other negative memories can relate to concrete experiences of physical force, being restrained, locked up and forced to take medication.

However, these negative experiences can go hand in hand with positive experiences of feeling safe, by being 'finally taken care of' and placed in a safe environment. It can be felt as a relief and an actual turning point in life, helping to end the chaos of psychotic experiences. Therefore the same person may describe the experience of first contact as either positive and or negative, depending on which aspect they recall at any given moment.

None of the respondents were aware of any other options to help them with their difficulties at the time of their first contact with mental health services.

This subjectively experienced lack of any alternative was discussed amongst UFM Team. The experience of being vulnerable and without support was explained in more depth. At that time people felt isolated and were not given sufficient information to help explain what was happening. Another point that was highlighted was the need to talk to other people who had similar experiences. As this exchange during the discussion illustrated:

- 'I was just sitting there. No support. What a waste of life.'

- 'You think that you are all by yourself. You haven't got anyone to talk to.'

Many would have liked to share their experiences with other people who had been psychotic - to know that they were not alone and that the problems they encountered where not unique. Some explained that the only possibility to talk had been with other inpatients at the psychiatric ward. But it was their experience that this is generally discouraged and hindered by hospital staff who do not want inpatients to 'hold court'.

Respondents made clear that, in an ideal world, they would have liked better treatment and support. Only two were entirely satisfied:

- 'The support was brilliant.'

- 'I had all the support that I needed.'

Others emphasised several areas of improvement:

- 'Not to have been taken to hospital, talk one on one with one person, be at home and treated there.'

- 'I would have liked when I was first going into hospital for someone to try and make me understand what was happening.'

- 'To be treated with respect, dignity, understanding to talk about how I was really feeling.'
- 'Someone to talk to, someone to understand me, someone to guide and support me.'

- 'Long-term support from same CPN/care co-ordinator and psychiatrist rather than changing every several months – more in-depth knowledge of services available.'

- 'Someone to help with handling the DHSS.'

- 'Family should see psychiatrist has they are the ones who need it.'

- 'Support to help me keep working and to keep on with my everyday life. Support in the community. Not to be told what to do.'

- 'A safe house.'

10.1   Key Issues When Dealing with First Episode Psychosis

Through a discussion of findings, the UFM Team identified five key issues which proponents of mental health support for people with first episode psychosis should take into account.

1. *Receiving information*: It is crucial that the service user is given clear and detailed information about the situation they are in and the support and treatment they are going to receive. This includes listing the various options for support and treatment that are available and giving detailed information about the effects and possible side affects of any medication proffered.
2. *Being listened to*: The mental health staff need to demonstrate empathy and should appear respectful and sincere in their approach to mental health service users. Service users are sensitive to the staff's honesty and willingness to engage in a non-authoritarian dialogue with them.
3. *Continuity of contact with staff*: It is important that service users wherever possible are assigned to one key worker to   allow stability and the opportunity to develop a individual relationship between staff and service user to assist the service user to feel confident and cared for.
4. *Considering the environment of the service user*: The service user needs to be understood as a person who has a particular personal and family background and is affected by specific social and economic circumstances. It is critical that the service user is not just seen as a representative of 'an illness'. In many cases, help to tackle issues as housing and income can be crucial to support recovery from mental health problems.

5.   *Considering the family*: In many cases the family or close friends are key caregivers and may also require professional help and advice on how they best can support the recovery. In other situations there may be considerable problems in the service user's relationship with the family, requiring support and advice on how to deal with this.

10.2   <u>Summary of Key Issues</u>

These five issues describing quality in mental health care can be summarised in three basic principles:

holism, respect, sincerity.

- When asked about if they would have liked to have the support earlier than they did the responses were generally positive.

- 'Yes, when I first needed help and someone to talk to and give me support – I had no one.'

- 'I would have appreciated it would have been better if my GP had taken action sooner by referring me earlier, to have seen a community nurse earlier. My mum kept taking me to see GP but he did nothing for me.'

- 'Yes – nip it in the bud before I had to go into hospital.'

- 'I would like to have been given intensive care to nip my escalating crisis – early on – including medicine (never got medicine till '90 – needed it in '87-'88. If I had been taken seriously over my "deep depression" and burgeoning delusions/superstitions), then it could have been treated <u>early on</u> and <u>prevent</u> an even more powerful breakdown in April '90.'

One comment emphasised the important message that it is not just a question of providing early treatment, but *high quality* early treatment and support.

- 'Did not know I needed support – but the <u>right</u> support earlier <u>could</u> have made a difference.'

Discussion amongst UFM Team members supported this view - emphasising that good quality support early on most likely would have meant that today they would feel much better and be in employment. One

respondent felt that it would not have helped to have earlier treatment and support since s/he was not ready to engage with services.

- 'No – it wouldn't have helped because I was putting up a front.'

This comment emphasises the need for mental health staff to appreciate the sensitivity of the people experiencing first time psychosis. It is necessary to approach each person very carefully and to respect their particular concerns and difficulties.

11. Contact With Mental Health Staff

The respondents' experiences of their first contact with mental health staff were mixed. Three of the respondents were unambiguously positive.

- 'Very kind and supportive both in community and hospital.'

Two others were moderately positive:

- 'Quite caring'

- 'Polite - unsure who she [mental health staff] was.'

But even when some respondents gave an overall positive assessment strong criticisms were presented.

- 'They were mostly pleasant, but there was a veiled threat if I didn't do what they wanted they would section me. Felt like they were telling me what to do, taking always my independence and treating me like a child.'

- 'Some nurses were kind but I found some nurses at [named hospital] were hard. I feel nurses do not talk to patients enough – just give injections/tablets.'

One did not remember the first contact with mental health staff and the rest of the respondents emphasised negative experiences. Recurring themes were problematic communication and anxiety about the situation

- 'NEGATIVE - Dishonest, Insincere, Judgemental, Condecending.'

- 'When I first went into a mental ward, I was left on my own. No one told me what was going on.'

- 'Most scariest ever.'

- 'Scary.'

- 'Very frightening.'

One explained how it had improved over time:

- 'Frightening, scary at first then friendly, understanding, empathetic.'

Only four respondents felt that the staff considered their life circumstances at the time of first contact with mental health services. The rest felt that staff had not addressed this initially.

- 'No – Felt I was a number.'

- 'No – I did not tell them anything until about 3 years ago.'

- 'No – not at first.'

- 'No – just the negative ones.'

- 'No – Not initially. If they had considered the life experiences it should have come from my mouth, not my notes.'

In some cases mental health staff present negative expectations to the future lives of the service users. Such stereotypical prejudices can have severe negative implications, as one respondent explained:

- 'Staff could have talked to me more, could have given reassurance. They told my parents I could never get better – negative – first admission 1981.'

Members of the UFM Team gave other examples of bad experiences with some mental health staff. One had been told by a psychiatrist that s/he would never be able to work. Such stereotypical and derogatory views presented by mental health staff can have severe negative consequences for the service user's sense of self and ruin hopes for the future. Another explained how mental health staff's insensitive questions can have unintended negative consequences for the service user. The question 'have you ever considered suicide?' meant that s/he for the first time started contemplating suicide as a possible solution to the difficulties s/he was experiencing at the time.

Some respondents were unsure how mental health staff, at the time, could best have approached them, since their psychotic problems dominated their lives.

- 'Frightened of everyone.'

- 'Blackness pervades, positive, honest, sincerity, non-judgemental.'

- 'Don't know. For myself I don't think there would have been an 'ideal first contact' because how frightened and disturbed I was.'

However, the elements of quality in mental health care described earlier are repeated:

- 'To have had things explained to me better and to have things discussed with me in a non-clinical environment and to be treated as an adult with my own thoughts and opinions, not someone who was incapable of making a rational decision – nor to be threatened.'

- 'They should have taught me and tried to make me understand what was happening.'

- 'Home visit.'

One respondent showed appreciation for the difficulty of the task:

- 'A scenario in which staff gave you 3 days of intensive discussion – I'm not saying that the staff's job is "easy" – it ain't!'

12. Psychiatric wards

Interviewees had an overwhelmingly negative view of psychiatric wards. The following is an example of words used to express what this had meant to them.

- 'Chaos in a controlled area.'

- 'Hell'

- 'Lunacy, mad, bad, and sad.'

Others related the experience of fear and humiliation and the lack of real help and support to recover:

- 'A place where you are left and get harsh treatment and a place where staff don't accept your opinions and what you want to do.'

- 'The place where I lost the most threads of my old life. Being trapped. Having my independence taken from me – not being part of acceptable society. Somewhere [where] responsibility is taken from you. Cut off from the world outside & real life, but can feel safe there even though it's a place where I feel despair and lost & disempowered.'

- 'Frightening – humiliating, made me worse to start with – been in hospital 12 times – last time the only time I've come out better when admitted.'

- 'It didn't help me as all they did was to give me pills – I just felt shut away from home.'

While two respondents had had a generally positive experience it was also observed that being admitted to a psychiatric ward carried the problem of stigma.

- 'Felt safe, people talked to me, nice surroundings.'

- 'A safe haven to recover in, away from problems but noisy, lot of help available, stigma.'

- 'I think it means that you are classed as mentally ill if you are admitted.'

One respondent stated that psychiatric wards should not be used for people suffering first episode psychosis:

- 'Try to keep people away from hospital. Treat people in their own homes. Not enough Doctors and Nurses.'

Other respondents recommended various improvements:

- 'Group new patients together, take a special interest in new patients, can be very stressful for them.'

- 'Single Room, one to one, empathy, understanding, no shouting, gentle, warm as an individual.'

- 'Individuals to have things discussed and explained to them on the ward. More contact with staff and for staff to have the time to talk and listen to individuals. To have some of the fear taken out of being on the ward. To be seen as a place of safety and help, not to be made feel a place of enforcement. To help empower people.'

It was noted that people experiencing first episode psychosis are particularly vulnerable and sensitive. Mental health staff need to consider this in their initial approach and ensure they listen to any concerns and explain what is happening.

- 'Don't push nervous frightened people into things. Treat them with a calm attitude listen to people and what they want and what they can't do.'

- 'A care worker should try and explain what is happening to you and what their trying to do.'

- 'Staff to explain what to expect within these wards and how the staff can help directly and indirectly.'

In the case of early intervention special adjustments could be made:

- 'With early intervention in psychosis, wards could be used as preventive care rather than the client getting ACUTE before admission becomes necessary. Wards could do with being more intensive early on. And providing more opportunity to talk + really <u>share</u> problems.'

- 'More geared to age + gender. Not just the area you come from.'

One respondent pointed out that inpatients in psychiatric wards do not only need mental help and support. They have also physical needs which also need to be considered by staff.

- 'They could acknowledge people's physical needs.'

13. Medication

The respondents were asked what medication means to them. Four reported the positive effect that medicine had on their mental health by indicating that it made them feel better.

- 'Getting better.'

- 'A possibility of improving my mental health – didn't see it as a cure, but as a way of lessening my mental pain + sufferings.'

Others pointed out that either the medicine had not had any effect or it had unpleasant side effects:

- 'They put me on drugs oral which did not help and later on they put me on injections which did not help.'

- 'A lot of the time it made me worse, I was confused and didn't know what I was doing.'

- 'Devastating – could hardly function as a human being.'

One emphasised the lack of information given about the medication.

- 'Pills (like paracetamol), didn't know what they did or anything.'

This issue was discussed further in the UFM Team where a common concern was raised about the way some psychiatrists and other mental health staff approach medication. Some felt there is not given enough attention to talk about possible side effects and whether or not the medicine can induce long-term damage to organs. They feel at times as though they are taking part in experimentation and that their safety and physical health is not given sufficient priority.

To some respondents, the use of medication carried problems of stigma in the sense that taking the medication meant that they were mentally ill. The medicine came to symbolise their illness, to themselves and to others.

- 'Stigma – caused problems at work on top of what I had already had – work not supportive, made me resign.'

- 'Realisation that illness wasn't going to go away overnight – it was a long term illness.'

- '[Medication meant to me] That I was a failure and couldn't cope on my own. Dolled my senses and made me put on weight. Options or side effects were never discussed with me.'

During the discussion of these findings in the UFM Team the issue of control was highlighted. Some have the notion that medicine takes over the persons' control over themselves, their minds and their bodies. Because of this some service users find it highly important to distance themselves from the medication and to emphasise that they are in control of their own lives – as illustrated in this respondent's statement:

- '[The medication meant] Nothing – medication dominated my mothers life – <u>not mine</u>.'

The issue of control makes the need for detailed information about the effects and possible side effects of medication even more paramount. Having information gives a sense of control. Equally, it is crucial that the service user is listened to and considered as an equal partner to discuss any treatment options. The respondents recommended that the new team for early intervention in psychosis considers the following in their approach to medication:

- 'Describe what the medication is for, what they do, what side effects. Full explanation and how the person would/might feel whilst taking them.'

- 'Discussing treatment.'

Another key recommendation was that great care is given to consider each individual's particular needs and alternative treatment options:

- 'Take every person as they come.'

- 'Look at the individual – what suits one may not suit all – took 20 years to find the one that suited me.'

- 'Consider any options open to individuals, not just that of medication. To discuss these with individual and listen to their wants and opinions. Only use medication if no other options available and explain clearly to individual side effects etc.'

It is important that the medication is given in the lowest possible effective dosage.

- 'Try and do with as little medication as possible because I think that too much medication can cause a worse situation.'

The importance of this point was emphasised through the discussion in the UFM Team. Many have had very unpleasant experiences with high dosage medication and they recommended that it would be better to start with a low dosage and, if necessary, gradually increase. Another issue can be the difficulty of administering many different types of medication.

- 'They should not give a patient a lot of medication to look after as I was always mixing it up and taking too much.'

Finally, one respondent underlined the need to provide information about the medication not only to the service users, but also to significant people in their lives, such as family members and work colleagues.

- 'Contact work for you and explain use and support.'

The UFM Team agreed that it in many cases it would be very helpful if the new team for early intervention in psychosis would take a holistic approach and give information and support to people and/or environments which are in contact with the service user. This may help to prevent or minimise prejudice and future difficulties.

14. Understanding the psychosis

When preparing the questionnaire it was agreed in the UFM Team that it is crucial for people having had first episode psychosis to be given an opportunity to talk about and try to understand the experience.
        In many cases the psychosis was very disturbing and frightening and talking about the experience would have been a help to overcome it. Unfortunately, this opportunity has not often been available in the present mental health services. Some of the participants in the UFM Team explained that taking part in the Team discussions had been their first opportunity to tell other people about their experiences during the psychosis.

Seven respondents (41%) indicated that they had had an opportunity to talk about their experiences and of these five (29%) stated unambiguously that they felt they had been listened to. One of them had had a particular good relationship with a key worker:

- 'My CPN at the time was excellent, he was kind, sympathetic and understanding.'

The other respondents would have liked to find similar qualities in the person they would have liked to talk to about their psychotic experiences:

- 'To Listen, not divert my thought process, allow me to express myself.'

- 'Someone who has the patience to listen to me.'

- 'Attentive, empathetic, experience in appropriate treatment.'

- 'A loving attitude.'

- 'Sensitive'

- 'Gentle'

This reflects the three principles of quality in mental health as mentioned above: **'holism, respect and sincerity.'**

15. Coping with Mental Health Problems

About half (n=8) of the respondents indicated that having a personal interest had been key in helping them to cope with their experiences of psychosis:

- 'Jazz and photography'

- 'Photography'

- 'Family, music, film, writing'

- 'A firm religious belief.'

- 'My animals keep me going – my key worker, the hospital.'

- 'Voluntary work, wide range of support to enable me to pursue what I am able to do.'

The discussion in the UFM Team emphasised that it is crucial that the new team for early intervention in psychosis takes a holistic approach to consider the service user as a person with a life, with interests and with hopes and plans for the future. It is important to focus not only on the problems and symptoms of mental illness but also to encourage the strong points in the life of each individual. This can help them to overcome the mental health problems they are struggling with and to lead positive lives.

Some emphasised how the personal attitude, such as having a good sense of humour, can be a strength when coping with mental health problems and difficulties in using the services:

- 'Passage of time (kills pain); increasing self-esteem; sense of humour; increased experience of life/survival; assertive approach to my care. I have coped better, obviously, as my illness has moved from acute to recovery.'

Other respondents highlighted the important role good mental health services can have in supporting a positive life. This includes contact with mental health staff and other service users in the voluntary sector.

- 'My psychiatric nurse [named] who is easy to talk to and understand problems.'

- 'Seeing my key worker and art therapy.'

- 'Other Service Users. Clubhouse environment. (Attending conferences and seminars).'

- 'Other service users. That I am not alone.'

Respondents listed a number of different types of services which had been a help for them coping with the mental health services.

These included:-
- Statutory Services
- Voluntary sector – mental health specific
- Voluntary sector – general
- Churches
- Housing associations

16. Conclusion

The respondents' final suggestions for the development of the service reflected the points addressed earlier:

- 'Treat people like human beings. Talk to people on an equal level. Look for alternatives to medication, which should be the last resort. Look after people more in hospital when they first come in. Hospital should be a last resort.'

- '1) "User-led services" where users come first and can be involved in their own care. Put the user back at the centre of matters. 2) On first admission to hospital clients should have much more emphasis on things like PMA (cognitive therapy) etc. – not just a regime of monitoring client response to tablets/injections etc. 3) Save a lot of time + money by having an effective "early intervention" scheme involving GP referrals. 4) User-led crisis services. 5) More out-reach services.'

16.1 Key issues can be summarised as follows:

1. Respect and listen to the service user.
2. Consider the individual situation of each service user taking a holistic approach.
3. Show care and sincerity.

4. Give detailed information about situation and treatment options.
5. Use low dosage medication and give information about effects and possible side effects.
6. Focus on the service user's strong points and on recovery – **psychosis is not a permanent state**.

This last point was discussed in further detail within the UFM Team ;it was mentioned that it is crucial that the staff remember that even if the service user is vulnerable following the psychosis this does not mean that they are permanently vulnerable people. This emphasises the point made earlier, which is imperative for the recovery process that service users are supported in recognising and developing their strengths.

Service users identified three key principles to describe quality in mental health care: holism, respect and sincerity. The Early Intervention in Psychosis Team needs to consider these principles in their team development process.

16.2 Holism

- The illness perspective has to be integrated into a wider consideration of the life of the service user.
- The service user is a person with a background that influences his or her mental health problems.
- The social and physical environment of the service user is crucial for the prospect of recovery (money, housing, employment, education and colleagues).
- Family and close friends have important roles in supporting the recovery process.
- The strengths (and not the weaknesses) of the service user ought to be the focus of recovery.

16.3 Respect

- The service user is a person and has to be treated as an equal by those working for Mental Health Services.
- The service user has to be given clear and detailed information.
- The effects and possible side effects of psychotropic medication have to be explained clearly.
- The service user has to be involved in discussing treatment options.
- The service user's concerns must be addressed.

- The service user's plans and wishes for the future have to be considered in the plan for treatment and recovery.

16.4 Sincerity

- EIIP Team members must be honest with the service user.
- EIIP Team members should show genuine care for the service user.
- Continuity of care through a long-term key worker facilitates a supportive personal contact for the service user.

These three principles represent the need for these approaches to be applied in all Mental Health Services. More specific recommendations regarding early intervention in psychosis are summarised here:

16.5 Specific Recommendations

17.5.1 Medication
- Use low dosage medication.
- Inform about effects and possible side effects.
- Respect the service user's concerns about taking medication.

17.5.2 Psychiatric wards
- Try to avoid hospitalisation.
- Consider that the service user is very sensitive and needs good support.

17.5.3 Psychotic experiences
- Provide service users with an opportunity to talk about their experiences in a supportive environment.

Appendix 1

MaryFrancesTrust
innovation in mental health through involvement

How effective have mental health services been in YOUR life?

Remember, YOU are the EXPERT

We are seeking your input to make sure the proposed 'Early Intervention in Psychosis Team' develops in partnership with Service Users' Views

Please make sure you have a copy of the leaflet that accompanies this questionnaire

Contact the Mary Frances Trust User Focused Monitoring Team on

01372 375400

Early Intervention in Psychosis

A User Focussed Monitoring project to
identify service user opinions for the development of
The Early Intervention in Psychosis Team

Questionnaire

Please remember you can leave out any questions you do not feel comfortable answering

1   Please tick your age group.

16 – 19 ☐   20 – 25 ☐   26 – 30 ☐   31 – 35 ☐

35 – 45 ☐   45 + ☐

2   Please circle   male   female

3   How would you describe your ethnicity ?
…………………………………………………..

4   Marital status – please circle

single   /   married   /   divorced

children   yes   /   no

About your first contact with Mental Health Services

5   What was your approximate age or the date you first came
     into contact with mental health services?
     Date ……./……/………..   or   Approx. age …………

6   Before your first contact with mental health services were
     you aware that you needed help ?

     yes   /   no   / Didn't think I needed help
7   Who made that contact ?
     …………………………………………..

8   What were your feelings about this ?
     a)   were you –
                    willing   /   unwilling

b)   did you change your mind during the process ?

yes   /   no

9   Looking back do you think that it was a

positive experience   / negative experience

10   Were you aware of any other options you could have used ?

yes   /   no

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11   How did your problems affect your mental health at that time?

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In an ideal world……..

12

a)   What support would you have liked?

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b)   Would you have preferred to have the
         support earlier than you did?

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c)   How would you describe your first experiences
         of mental health staff

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d)   What would have been your ideal first contact
         with staff ?

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13   Do you feel the mental health services
      considered your life circumstances and
      experiences?

                              Yes   /   No

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14   What did medication mean to you?

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      How do you think the new team should approach the use
      of medication ?

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15   What do psychiatric wards mean to you?

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How do you think they could be used differently for people experiencing a first episode of psychosis?

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Understanding of psychotic problems

16 a) Did you have the opportunity to talk about
         your experiences?

                    yes   /   no

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   b) Did you feel you were listened to?

                    Yes   no

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    c)   What qualities would you have appreciated
          in the person you spoke to?

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17   Who or what has helped you cope with your
      experiences of mental health services

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18   Who or what has helped you cope with your
      personal experience of psychosis?

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19   Do you have any further suggestions for the development of the service?

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Thank you for taking the time to complete this questionnaire…..

…. the time you have spent has been greatly appreciated

1   Thank you

Without your help this would not have been possible.

If working with us and this questionnaire has raised

difficult memories of the past for you please talk to a staff member. If you have no-one please contact Jackie at the Mary Frances Trust and she will find someone for you to talk to
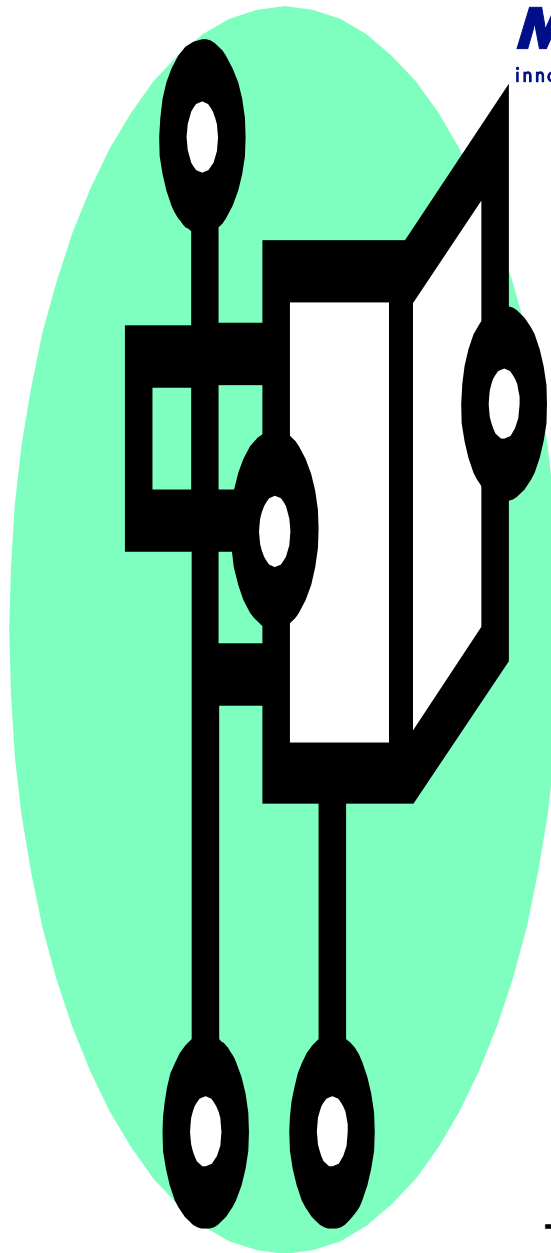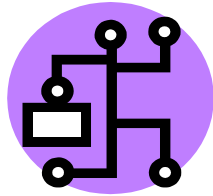
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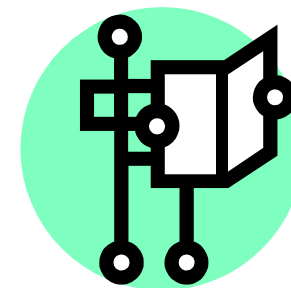
The Mary Frances Trust
User Focused Monitoring Team
Are working in partnership with

We are seeking your input to make sure the proposed

'Early

Intervention in

Psychosis Team'

develops in

partnership with

Service

Early Intervention in Psychosis – Mary Frances T

Please Remember

- Only fill in the questions you want to.

- Every questionnaire is

- anonymous

- There are no right or wrong answers

- We are only asking about your contact with mental health services

not personal

information about you !

Any Questions— Please Contact

Jackie Macklin

User Involvement

Co-ordinator

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