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scotland



action for people affected by mental illness

# Report

## Early Intervention in Psychosis engagement project 2021

Hamish Kidd, Support in Mind Scotland



## Early Intervention in Psychosis engagement project

### CONTENTS

Forewords	page 2-3
Introduction	page 4
Methods	page 5
Thanks to participants	page 5
Executive summary	page 6-7
Summary of recommendations	page 8-9
1. Seeking out specialist support: the path into services	page 10-16
2. Consequences of inaccessible care	page 17-18
3. Responding to diagnosis and understanding it	page 19-21
4. Medication and treatment	page 22-25
5. A service that meets individual needs	page 26-30
6. Optimising family and carer involvement	page 31-34
Summary of action points – what do policy makers need to address?	page 35-36
Related action points – what else do policy makers need to address?	page 37-39
Conclusion	page 40-41
Acknowledgements	page 42
Footnote	page 43

**\*\*\*Lived experience quotes are represented in red to highlight their importance.\*\*\***

# Early Intervention in Psychosis engagement project

## **FOREWORDS**

A first episode of psychosis is a significant life event, with ramifications for individuals and families as well as society. I know this from personal experience, and my episode of psychosis has influenced my career trajectory and work I have chosen to do. When Healthcare Improvement Scotland (HIS) were first commissioned to do work on the propagation of early intervention in psychosis, Support in Mind Scotland (SiMS) created a Lived Experience Reference Group and I was delighted to be asked to contribute.

Over the past months and years, we have been feeding into HIS lived experience perspectives, and a key part of this has been our recent engagement events. We engaged with around 130 individuals from across Scotland, who provided their perspectives on early intervention. Led by Hamish Kidd (SiMS), we have created this report based upon these views and we are grateful to everyone who has taken part – we recognise that this hasn't been easy.

Four aspects stood out to me. Salient aspects of what people said related to the needs for additional information across the board, as well as the consideration of individual circumstances, including personal definitions of recovery. Issues around medication and human rights considerations were also raised.

A comprehensive account of our findings is detailed within this report. It is my hope, that this report is widely read and helps to improve early intervention, outcomes and lives.

*Louise Beattie*

*Chair*

*Early Intervention in Psychosis Lived Experience Reference Group*

## Early Intervention in Psychosis engagement project

### **FOREWORDS**

Support in Mind Scotland was invited to be part of the Scottish Government's Early Intervention in Psychosis short life working group at the very end of 2018 to help to develop an action plan to explore and promote early intervention approaches for improving the care and treatment of people experiencing first episode psychosis, and we were delighted to be given this opportunity.

We have been supporting individuals and families impacted by psychosis for nearly 50 years, and the dominant experience of the people we have supported over the years is of being ignored or let down by mental health services, that simply did not understand people's experiences. In 2014, we completed a report we titled 'One in 100', gathering the experiences of people with schizophrenia and psychosis and their families with the aim of putting pressure on decision-makers to address this neglect. But the report did not turn the tide in spite of widespread support from individuals, families, practitioners and clinicians who knew a new approach was urgently needed.

The 2018 working group did not involve many people with lived experience initially, but as the work evolved, we reached out to as many voluntary groups as we could to ensure that the voice of lived experience was heard loud and clear, leading and informing essential change. The result is this report: hard to read, powerful and moving testimony that tells us sadly that very little has changed since our 2014 report – or the comprehensive review of schizophrenia services a full decade earlier in 2004 – with lack of understanding and lack of clear pathways to support still the headline findings.

Hamish says the word he heard most was 'listen' – and it is imperative that this is the last time we go through a review like this, just to file it away and disregard the real life experiences that people have shared. This time we must listen – and act swiftly on what we hear.

*Frances Simpson*  
*Chief Executive, Support in Mind Scotland*

## Early Intervention in Psychosis engagement project

### INTRODUCTION

The aim of this project in 2020/21 was to engage with people, from across Scotland, about what needs to be in place for people experiencing a first episode of psychosis. The Covid -19 pandemic required the engagement to be carried out remotely, using digital methods. The programme of engagement was directed by the Early Intervention in Psychosis Lived Experience Reference group (EIP-LERG.) A lived experience engagement worker was employed, by Support In Mind Scotland, to work with the EIP-LERG.

The EIP-LERG consists of individuals who had either a personal lived experience of psychosis, or had supported a family member with psychosis; some had both. They were approached by Healthcare Improvement Scotland to carry out a programme of engagement work due to their experience and connections in the field of mental health in Scotland. They formed a relationship with Healthcare Improvement Scotland, due to their personal and professional interests in improving services for people experiencing psychosis. Output from the engagement events would accompany reports from Healthcare Improvement Scotland into needs assessment visits to Scotland's NHS boards.

The title, "The Road to Early Intervention in Psychosis Services in Scotland," was chosen at a time when only one Early Intervention Service existed in Scotland. It was known that services differed across Scotland. The solutions needed to improve services would depend on the populations and geography of the communities they served. The concept of a journey turned out to be apt in describing the resilience and fortitude people needed to gain access to mental health services and to manage severe and enduring conditions.

Existing reports on services for people with psychosis in Scotland included:

- **1 IN 100** - The experience of living with schizophrenia and psychosis in Scotland: Results of the Scottish Schizophrenia Survey, written by Amanda Larking in 2015.
- **It's their job - it's my life.** The results of a 2010 survey into carer's experiences of communication published by Support in Mind Scotland.
- **Carers and communication.** A report published by The National Schizophrenia Fellowship in 1999.

In contrast to previous reports, the current engagement work focussed on how services could be accessed more promptly and easily (to reduce the duration of untreated psychosis.) We asked people about what they perceived as the benefits of accessing services sooner and what would have assisted them in their recovery.

People told us that experiencing psychosis for the first time was a life changing event for themselves and those around them. The full significance of the first episode wasn't always realised at the time. With the benefit of hindsight, however it was seen as an epiphany. What they experienced at this point, and how they were treated by others, was memorable. It played a significant part in informing their view of the world, society itself and their role and purpose within it. It gave them a profound understanding of what it meant to be human, and that the experience of psychosis was shared by many others and was intrinsically human.

## Early Intervention in Psychosis engagement project

### METHODS

A plan was made to carry out virtual engagement during December 2020 and January 2021, Zoom was used as the event platform. A series of three questions were proposed by the EIP-LEERG. We asked people with lived experience of psychosis, and their immediate family members:

- i. How can care be made more accessible?
- ii. What does early intervention mean to you?
- iii. Thinking of your experience, what would have helped?

Responses were received through three channels:

- i. Group discussions held on Zoom (73 participants.)
- ii. One-to-one telephone interviews (14 participants.)
- iii. An online questionnaire (45 responses.)

The group discussions were facilitated and transcribed by members of the EIP-LEERG. The notes from all three channels were analysed (by a lived experience engagement worker) for recurrent themes. An overarching temporal aspect was identified, with nine main themes. These are now summarised in turn below.

### THANKS TO PARTICIPANTS

The information in this report has only been possible because people with lived experience, their families and carers who *volunteered* their time to engage with us. Their motivation to participate was altruistic: to improve the systems that exist for people who experience psychosis in the future. There was a strong desire for this work to continue. That is, for services for people with psychosis to directly meet the needs of the people they serve. In order to deliver services that meet the needs of the Scottish public in 2021, there needs to be a commitment to working in partnership with people who use these services. There is an opportunity to develop existing services and to implement new services that place people with lived experience at the heart. In order to provide this and to take a human rights based approach, there needs to be ongoing oversight and scrutiny from people with lived experience. **This is a point of critical importance for leaders, policymakers and clinicians to understand: the views in red are those of your constituents, your fellow citizens and most importantly of all: your peers and equals.**

**“Early intervention means working with someone to prevent a life in the system.”**

**“It is not only people with first episodes of psychosis who find it difficult to access services.”**

**“I know the Scottish Government commissioned this piece of work but they must get the information, whether palatable or not, people with lived experience and carers deserve nothing less.”**

## Early Intervention in Psychosis engagement project

### **EXECUTIVE SUMMARY**

Individuals described a range of experiences linked to the current lack of early intervention in psychosis across Scotland. Barriers to accessing services included a lack of information about psychosis and a loss of insight, with no clear pathway for significant others to convey information to medical professionals. Thus patient confidentiality was seen as hampering timely care. While family members/carers had an important role, it was recognised that not everyone would have access to this, and they would require additional support given current gaps in care provision. As the concerns of close or significant others were often not acted upon by primary care services, GPs were seen as gatekeepers.

As a consequence of inaccessible care, individuals could reach a crisis point, and the enhanced fatigue and distress linked to a protracted entry to services could create a vicious cycle, with individuals less able to become meaningfully involved in their own care. This creates an added burden on services, in terms of crisis care and/or hospitalisations, but also potentially for the police. This also creates a significant added burden on family members, when care is inadequate. As such, early intervention was valued and perceived to enhance the nature and setting of care, as well as promoting family life. Personal recovery was therefore important, in terms of being able to plan a life with individualised goals and aspirations. This underlines the pivotal role that human rights considerations take.

In tandem, individuals and their families had fears and concerns around accessing mental health services. This included a loss of independence and autonomy, with fears of disclosures being used against individuals in future. This could be related to drug or alcohol use, as well as trauma, with trust facilitating engagement. Being initially listened to was seen as important, and identifying underlying causes takes time. Life events and transitions were linked to a first episode of psychosis. Experiences of psychosis and its treatment with sedating medications could lead to missed appointments, and be misperceived by services. This emphasises the need for personalised approaches. Peer support was valued by those with lived experience as well as carers and family members.

Upon receipt of a diagnosis, individuals again sought more detailed information about psychosis, as well as signposting to sources of advice and help. Diagnostic changes could be a source of stress, which impacted care, with a perception that individuals were treated through lens of a diagnosis rather than their personalised needs. Those who had previously experienced psychosis within the family desired additional information, as did parents of children. This highlights the unmet information needs.

A range of diagnoses were represented, and medication featured prominently as the treatment on offer. However, there was often a lack of information about this, and an absence of alternatives on offer including clinical psychology. Medication was therefore seen to be used coercively, with concerns about medications and side effects, and a lack of information. Individuals sought support to withdraw. Physical health and mental health were important. This stresses the importance of sensitive approaches to medication within psychosis.

*Louise Beattie*  
*Chair*

*Early Intervention in Psychosis Lived Experience Reference Group*

## Early Intervention in Psychosis engagement project

### EXECUTIVE SUMMARY

#### CONCLUSIONS:

“We engaged with around 130 individuals from across Scotland, who were willing to provide us with detailed personal accounts of their perspectives on early intervention and what it means to them. This was despite this engagement work taking place over the difficult Christmas period, in the midst of a pandemic. We are grateful for their time. From this, some key conclusions can be drawn. Firstly, there were clear information needs relating to psychosis and its treatment, for medical practitioners, the general public, individuals and families. Secondly, a personalised approach was valued for individuals and families, across domains including recovery and consideration of triggering and maintaining factors. Thirdly, individuals reported that treatment was heavily focused on medication, with a lack of alternatives including psychology, or addressing of the side effects. Fourthly, the human rights aspects are highlighted, in terms of availability of treatments as well as around the potential legal aspects within psychosis. Taken together, the existing knowledge of those with lived experience of psychosis and their supporters should be foreground in future planning a road to early intervention in psychosis in Scotland.”

*Louise Beattie*

*Chair*

*Early Intervention in Psychosis Lived Experience Reference Group*

“This piece of engagement work was undertaken around the festive season and during a pandemic when face-to-face discussion was impossible but despite this, has generated very rich & informative feedback and meaningful insight. Even more importantly having identified the flaws in the current systems, people with lived experience of psychosis were able to identify what would have made a difference, what could have prevented lives being wasted, what would have improved their care, what would have shortened inpatient stays, plus so much more.

The need for early recognition of psychosis and the need for early intervention in psychosis are givens and all efforts must be focussed to make these a reality throughout Scotland whilst recognising that ‘one size will not fit all’ given the different populations in cities and rural areas.

Another given is that care must be person centred, the service should be managed for the service user not the service provider which is how care is perceived currently. Yet another given is that there is scope for properly funded third sector involvement.

Finally, those with whom we engaged must be listened to, to be heard, to be part of a fundamental change in how people with psychosis and their family/ carers are treated – lives will continue to be wasted and some lost, if not.”

*Jean Campbell*

*Early Intervention in Psychosis Lived Experience Reference Group*

*Lived experience carer and Support In Mind Scotland volunteer*

## Early Intervention in Psychosis engagement project

### **SUMMARY OF RECOMMENDATIONS**

Four main areas of change are being sought by people with lived experience in the development of early intervention services in Scotland:

1. Informing, educating and raising awareness of psychosis as a public health matter.
2. Services that meet the needs of people who use them and are accountable to the communities they serve.
3. Services that work effectively with families as well as individuals.
4. Services that measure demand and performance in meaningful terms to the communities they serve and are accountable to public scrutiny.

#### **1. Public awareness of psychosis needs to be raised and the associated stigma addressed.**

- Psychosis needs to be understood as a response to a combination of factors. The central theme needs to be one of empowerment: positive action improves outcomes.
- Awareness raising, information and education should be targeted at school children, teenagers and young adults.
- Information for the public needs to describe the experience, be realistic, emphasise how to access support and why this needs to happen quickly.
- Frontline staff need to be well informed about how to recognise psychosis and to triage effectively. They need to be ready to act on warning signs reported by family members. The overall goal needs to be to reduce the duration of untreated psychosis.
- Staff delivering care for people with first episode psychosis need specialist training and supervision on the practice of early intervention.

#### **2. People who experience first episode psychosis need person-centred care delivered by a well-coordinated partnership of statutory and third sector organisations.**

- Rapid access to specialist assessment, care and treatment.
- A designated keyworker as a point of contact.
- Their experiences and beliefs to be compassionately listened to and understood.
- Phone numbers for appointments, out-of-hours and emergencies.
- Clear information about first episode psychosis and education about underlying causes and associations.
- Their home environment, background and history to be well understood.
- Integrated treatment for general health conditions and any co-morbid mental health conditions, including substance and alcohol use.
- Their rights to be protected and their preferences respected.

## Early Intervention in Psychosis engagement project

- Hope that recovery is possible and uncertainty is manageable.
- Goal setting and recovery planning based on their priorities, values and ambitions.
- Advanced statements and Wellness Recovery Action Plans.
- Care and treatment that directly addresses their needs and alleviates their distress.
- Therapy to help them to process, understand and self-manage their mental health.
- An informed approach to medication that balances potential benefits and risks.
- A combination of approaches to treatment: psychological therapies, family interventions and peer support.
- Access to a network of community organisations that offer social, creative and vocational activities.

### **3. Family members, partners and supporters of people with first-episode psychosis need to be identified quickly and worked with pro-actively by services.**

- They need to be directly involved in planning, delivery of care and therapeutic treatment as far as is possible.
- They need access to carer support planning, information services, educational resources and advice on financial and legal implications.
- They may also benefit from access to advocacy, respite breaks, emotional support, peer support groups and social activities.

### **4. A human rights based approach should be at the heart of the design, implementation and delivery of services for people with first-episode psychosis.**

- General medical practices and frontline health and social care staff will need quick and efficient access to regional services for people with first episode psychosis.
- The link between rapid access and improved long-term outcomes needs to be emphasised.
- Special consideration needs to be given to family members who report concerns as individuals may not know they are unwell, or lack insight.
- Barriers to access may need to be analysed and overcome, when referrals are made.
- There needs to be a clear and coherent pathway that focusses on personal recovery and the needs of the individual.
- This pathway should ensure that people who don't fit the diagnosis of first episode psychosis are provided with effective care and treatment.
- Services need to be trauma-informed and able to provide specialist care for people who have experienced trauma.

## Early Intervention in Psychosis engagement project

- There needs to be a multi-disciplinary approach based on teamwork, that can provide intensive support in home and community settings, to reduce the need for hospitalisation.
- Inpatient beds must be available for those presenting with symptoms of risk to themselves and/or others.
- There needs to be a system that embeds learning so that innovative approaches can be piloted and trialled in response to emerging research evidence. Specific reference to Open Dialogue was made by both individuals and their families.
- There needs to be a commitment from the outset to collect and analyse data on people presenting with first episode psychosis to understand demand and plan provision accordingly.
- Personal outcome measures are key to understanding the value and effectiveness of service delivery.
- NHS services should work in partnership with third sector organisations to facilitate access to assets that meet the needs of both service users and their families.
- Involvement, engagement and participation of people with lived experience and their families should be central to partnership working.
- Stakeholder mapping and engagement should be utilised to inform how services are delivered in each region.
- Examples of existing partnership working include self management, peer support, carer support, hearing voices groups, collective advocacy, individual advocacy and Individual Placement and Support Services.

## Early Intervention in Psychosis engagement project

### 1. SEEKING OUT SPECIALIST SUPPORT: THE PATH INTO SERVICES

**“The thing about when you’re delusional, is that you don’t know that you’re delusional.”**

People who were experiencing psychosis for the first time did not understand what was happening to them. Although many were aware that something was happening, the experience did not always feel like a mental health issue.

**“More than a year before I went to my doctor, I started to worry that there was something wrong with me. My boyfriend had a psychology textbook - I sat up and read it when they were all asleep. There was nothing in it... that described how I felt. I walked to work everyday. One day I couldn’t find my way back to the flat, it was confusing. I couldn’t understand how I could be lost. I was just terrified of life.”**

Some people described a feeling of awakening, or a dawning realisation that they were seeing the world as it truly was for the first time. Many people felt the world around them had changed, not their perception of it. Loss of insight into their own state of mind was a common presenting symptom.

**“In most cases people who are in a bout of psychosis don’t realise, or are unwilling to admit they are unwell. It is down to relatives and friends or neighbours to flag up concerns and in my experience they are not listened to.”**

NHS services can respond to people’s symptoms, but not always to changes in behaviour, appearance or demeanour. These first outward signs were often noticed by family members and reported to their General Practitioner (GP), but were not acted upon.

The earliest chance for intervention was often missed due to services being structured around an individual who has awareness of their symptoms and can explain them to a GP. Many people told us that they did not receive rapid access to care, because the external signs of their illness were reported by people who loved and cared about them.

**“Professionals need to listen to carers and family members as they are most often the first to recognise when someone is becoming unwell and often know how to approach the situation but can be brushed off. Carers can quickly see what is happening and are often the way the person experiencing psychosis accesses help.”**

There is a specific need to inform the public about what psychosis is, how it feels from a personal perspective and what external signs are likely to be visible. The lack of presenting symptoms, the behavioural changes and the reluctance to seek outside help need to be highlighted.

**“TV campaigns focus on other elements of mental and physical wellbeing but not psychosis. There needs to be greater awareness nationwide.”**

For people who did experience symptoms, a lack of readily available public information and public dialogue on psychosis meant that they did not immediately seek support or referral from a medical

## Early Intervention in Psychosis engagement project

professional. A number of people did seek out support before they began to experience full-blown psychosis. Examples mentioned were worry, stress, low mood, loss of motivation; difficulty concentrating, thinking clearly or making decisions. Some people were prescribed anti-depressants by their GP during this early phase.

**“One difficulty is the 111 service can take up to 4-6 hours to get a response or referred to an out of hours team. A specialist response team dealing with psychosis would be good. A lot more training for nurses, doctors, police and other professionals who aren’t specialists in mental health. Drop in centres in GP surgery’s during the day run by CPNs, it can be very frightening for a person when they become psychotic. Easier access to CPN with out long and complicated referral process.”**

GPs did not always recognise psychosis symptoms. They may not hear the full story (particularly on the first visit.) Referrals often were not made after the first visit. Examples where people were referred by their GP mentioned:

- The GP knowing the patient before they became unwell
- Having rapport/trust
- Consistency
- Information being shared and recorded (messages passed on from reception/nurse)
- Receiving information from multiple sources (eg corroboration from person/ partner /family / counsellor.)

People who experienced positive symptoms and actively sought support found community mental health teams difficult to access. Individuals and their families often viewed GPs as gatekeepers to services. However, referrals made by GPs to mental health services were sometimes refused too. GPs who made referrals were often not picked up by Community Mental Health Teams/ psychiatrist or hospital. The phrase, “bounced back,” was repeatedly heard. Examples included:

- communication difficulties and distraction caused by hearing voices
- combination of paranoia / suspicion and short appointment time
- individual not being assertive enough to put across the severity / urgency of their needs
- criteria not being met for diagnosis
- presentation not being textbook (visual hallucinations were treated with suspicion.)
- psychiatrist disagreeing with GP about likely cause and appropriate management
- information coming from family member (individual not present)

**“GPs need to learn to be pushy. GPs might need to make more than 1 referral for an individual or be willing to defend the referral and push hard for a person to be seen and adequately assessed in shortest possible time.”**

## Early Intervention in Psychosis engagement project

People with lived experience of psychosis do not fit neatly into referral criteria! Referral criteria is a tool used to keep people with symptoms out of the service – unforgivable!

The mental health service must be patient/client focussed, not service-focussed. Care pathways are a good idea but there must be some leeway for individualised care - human beings are all individuals and must be treated as such. I suspect there needs to be a huge training shift within the mental health service to better communicate within and across services, with the person experiencing symptoms and the unpaid carers/family member/friend. Professionals must not hide behind 'confidentiality' and human rights of all concerned are important. “

“The fact that the person experiencing the psychosis could not self-refer nor can others, e.g. family, friends, social workers refer to any service.”

“ I only know that being invited to one-to-one interviews in the resource centre with psychiatrist and CPN was crucial to flagging up my psychosis.”

“Easier access - eg very high bar to referral from GP to mental health, (understandably) due to lack of mental health care resources.”

“There should be “walk in services” available within general practice.”

“More information needs to be given at the time of diagnosis and support given immediately: doctors are too quick to label a mental health illness.”

“Port of contact (emergency service for MH) with those trained to deal with MH issues who can help get people the right service for them at that time. Lack of understanding, empathy, judgemental attitudes and afforded time make it difficult for people to engage with GP, A+E, Emergency services with postcode lottery dictating level/quality of care received. “

“Lack of emergency professionals who are accessible to give advice particularly observation. For psychosis protracted observation can be key to really understanding even if it's coming to the residence for a few hours. Then acting to support their support network to move forward. Spaces for the person to heal and rehabilitate, more safe places/ community spaces to hold a person during recovery.”

“Raising awareness of the challenges faced by people experiencing psychosis so that everyone working within the health service can have a better understanding of how the person may be feeling and learn the best way of offering help. This could be managed by asking someone with lived experience of psychosis to speak to workers/students as part of their training. Offer people the opportunity to communicate in as many ways as possible like they do at the Edinburgh Crisis Centre so that they feel safe to get in touch eg text or Whatsapp which is encrypted now. I know from personal experience that this wouldn't always be possible but it may make the difference between someone accessing the service or not, particularly younger people. “

## Early Intervention in Psychosis engagement project

A number of concerns were mentioned which impacted people's engagement with mental health services. Many of these could be addressed:

INDIVIDUALS FEAR:	FAMILY MEMBERS FEAR:
Talking about their symptoms	Their concerns not being listened to
Stigma and image of psychiatric hospital	Loss of trust and relationship breakdown
Being compelled to access services	Being excluded from care planning / provision
Loss of freedom	Reaction of individual
Being sectioned	Inadequate care / wrong diagnosis
Compulsory medication	Not complying with treatment
Side effects of treatment	Treatment not working
Safety in hospital	Safety if discharged to community services
Bad experiences in healthcare	Withdrawal or disengagement from services
Financial / professional implications	Lack of carer support & burnout
The uncertain future	The uncertain future

The most common barriers to accessing services for psychosis were:

- Service capacity / pressure on workers.
- Confidentiality "loophole" of urgent information from family not being passed on or acted on. Not one person we engaged with wanted their family to be excluded from their care (with the benefit of hindsight.)
- Criteria not being met for diagnosis, or presentation not being textbook.
- Current or past history of alcohol or substance use. An example was given of a young woman supported by an addictions charity for 7 years. (Due to another family member's substance use.) She had no personal history of substance use. Despite repeated attempts to access to mental health services during this time. She was finally diagnosed with schizophrenia, retrospectively.
- Personality disorder / traits either diagnosed or suspected. More likely to be discharged, even when experiencing psychosis. Young women who present with psychosis are stigmatised with this diagnostic label and treated differently. Experience of having diagnosis revised after re-admission to hospital.
- Geographical / travel challenges. People having to make long journeys safely when unwell. Example of Wick to Inverness 250 mile round-trip to access specialist services. People who lived in remote or rural communities often had to travel significant distances, in order to access the specialist assessment and treatment they needed.

## Early Intervention in Psychosis engagement project

“For me the biggest barrier to getting support and help occurred after my first psychiatry appointment. Up till then I had had a good relationship with GPs. My first experience of psychosis happened in 2006, when I was 30 years old. I had grown up having issues with anxiety, then a number of difficult life circumstances happened, and my stability and support was no longer there. When I had my first psychiatry appointment my current life situation and the events that had led to my crisis seemed to be barely touched on. It felt like the psychiatrist couldn't see or hear me, all he could see was the very edges of me - the outlying behaviours, a symptom checklist.

I came away with a pink piece of paper that had 'Paranoid Schizophrenia?' on it, and I was both scared and angry as hell. My thought was, if you're not sure, why on earth would you put it on a piece of paper? At that time, to me, that label felt like a death sentence. I had been a successful student, a valued employee - that label had the potential to steal my life and my future. I think that was when my trust in the NHS dissolved.

I avoided contact with health professionals as much as I could for a very long time, I even stopped regularly visiting the dentists. Until very recently every visit to the GP has carried additional stress and worry. Where I can, I ask my partner to accompany me, as I find I can still very easily enter flight/fight mode in medical situations. I hope things have moved on a lot in the last 15 years, and that health professionals see an individual, with a life story. That they listen really well to how the symptoms are impacting that person, what has changed for them to lead to the crisis - to not just treat a collection of symptoms, to focus a bit less on labels and a bit more on helping the person recognise their distress as part of our shared human experience - something that can impact anyone.”

## Early Intervention in Psychosis engagement project

<b>INDIVIDUALS NEED:</b>	<b>FAMILY MEMBERS NEED:</b>
Frontline health and emergency services who can recognise symptoms of psychosis, understand the need for early intervention and refer urgently	Frontline health and emergency services who can recognise signs of psychosis reported by a family member. To understand the need for early intervention, respond effectively and refer urgently.
Stigma and image of psychosis experience addressed with accurate and realistic information. Information and awareness to target teens and young adults.	Information and awareness to highlight they may be first to notice signs. Address the needs of family members, the impact of psychosis and the need for early intervention.
Their symptoms and experiences to be listened to, validated and addressed.	Their input, observations and concerns to be noted and actioned.
To receive person-centred care and develop a trusting relationship between their own family and professionals.	To develop an ongoing trusting relationship with their family member and professionals providing care.
Information, self-management advice, care and treatment that directly addresses their needs and benefits them.	Support, information, guidance, awareness of rights, legal & financial advice relevant to their needs.
Choice, awareness of their rights as a patient and as an individual. Access to advocacy if required.	To be included as an equal partner in the triangle of care, planning and provision. Access to advocacy if required.
Care and treatment to be delivered in the least restrictive way that is effective.	Inclusion in discussions that address risk and clear communication if level of restriction is increased or decreased.
A clear, evidence-based appraisal of the balance of medication benefits vs side-effects in real time.	Clear warning signs of adverse medication reactions and what to do if they occur (eg dystonia.)
Name, dosage and regimen for any medication prescribed.	To know name, dosage and regimen for any medication prescribed.
Any reasons that specific medication has been chosen.	Any safety implications of that specific medication.
Likelihood of treatment working, available alternatives if it doesn't.	Likelihood of treatment working, available alternatives if it doesn't.
Physical safety in in-patient settings that are free from alcohol and substance use.	Transparent information about safety & wellness of person they care for.
Employment support, financial advice and guidance on rights in workplace.	Freedom and time to pursue their own ambitions and lives.
To be listened to and problems addressed if there are negative experiences in healthcare.	Confidence problems are addressed if they occur and that there are ways to manage disengagement.
The future to be optimistic, planned and contingencies in place if setbacks occur.	The future to be realistic, planned and to be fully included in contingency planning.

## Early Intervention in Psychosis engagement project

The combined toll from these factors not being addressed, resulted in delays to accessing services. This meant that care was often not available, until the person was in crisis. Many people told us they felt that there was a requirement for them to have reached the point of crisis, in order to get an appointment with mental health services. Even once they were in crisis, they could not always access mental health services through conventional channels.

**“Obviously a person needs to be risk assessed and made safe, in a neutral and calm place (not a police cell if possible and not A&E, if possible). Staff working with the person should be trauma-informed and aware of calming strategies for helping to ground people. Support staff that are trained listeners, who have time to understand what is happening for the individual. Support may be in different forms, online information for people in distress and their families, including where to go for help, possible causes and information on how to behave with someone in distress. To normalise the experience for the individual and for their loved ones. Don't rush to diagnose. Focus on alleviating the distress and helping the individual to find ways to self-soothe and to come to terms with the trauma of hitting crisis point. Find out what makes them feel safe, what they need to feel safe - it may be that their family situation is not the best place for them to be for recovery.”**

Unmet needs (due to being denied access) tended to become more urgent. Access to specialist services in in-patient settings tended to be by police or ambulance. Emergency services, particularly Police Scotland, were often the first point of contact. Many people spoke about the key role the Police played in recognising their symptoms and helping them to access services. Some people had positive experiences with the police. Awareness of psychosis and knowledge of how to access services were good. A minority had negative experiences with the police. These included being charged with wasting police time and police cells having to be used as a place of safety.

**“One of the barriers is confidentiality as doctors can't talk about their patient. Doctors can't intervene unless the care giver or another person is hurt. The easy way to deal with Psychosis is to call the police and then transfer to Royal Edinburgh.”**

**“Difficult to get taken seriously until I was nearly killed.”**

**“The police are better at recognising a person in distress / displaying psychotic symptoms than health care professionals.”**

**“People need to access help in a timely manner before things escalate. There was a feeling that help was only available in crisis “police, blue lights and doctor to section”.**

## Early Intervention in Psychosis engagement project

### 2. CONSEQUENCES OF INACCESSIBLE CARE

**"Schizophrenia is a thief that stole my brother away."**

People who experienced delays in initial access to services, were more likely to have to contact out of hours, crisis or emergency services. Although emergency services were available and able to help, it was widely felt that this was an avoidable strain on their resources. A number of people were taken to a place of a safety by the police, either a police station or cell: not a health setting. A small minority faced criminal charges as a consequence of their illness.

**(To make care more accessible there needs to be,) "Clearer pathways for care that are not as extreme as hospitalisation and being sectioned. Something more halfway."**

The channels available to someone presenting in crisis meant a long and complex triage process for them, in order to see a mental health professional. The overall need was for rapid access to specialist services as by this point people's mental states were deteriorating rapidly. For other family members this caused considerable upset and concern for the safety of their loved one. They expressed frustration that they could not influence the process and get help sooner. It was not always clear when someone presented to services what was happening or where they were being taken. This meant they could not share their knowledge and insight at the time it was most needed. Most reported sleepless nights and fear for the person seeking care.

**"Early intervention could avoid people needing going into hospital. If somebody asks for help and they do not get any they feel even more insecure and might give up asking for help, which will just worsen everything. I believe early intervention could give tools to deal and avoid more critical break outs. It would also be cheaper for the health system."**

**"Cannot stress how scared I was that my daughter would harm herself or someone else before I could get her the help she needed. But no proof so no help; medication was ignored each time as soon as brief hospital spell was over. Like living with volcano not knowing when next eruption."**

People arriving for specialist assessment or treatment were so tired and distressed that they did not understand what was happening to them. This meant that they were less able to assert their right to meaningful involvement in their own care. They were more likely to need in-patient care in an acute ward, or intensive psychiatric care unit. Some faced emergency or short-term detention under The Mental Health Act. Hospital stays tended to be measured in months rather than weeks. Medications tended to be used in combination and at high dosages. Some people described the use of chemical restraint, others viewed medications at this stage as a cosh; rather than an essential part of treatment. (These experiences are supported by The Mental Welfare Commission's consultation on Capacity, Detention, Supported Decision Making and Mental Health, published in 2017)

## Early Intervention in Psychosis engagement project

**"The entire NHS mental health system is under-staffed and overstretched, not just wards & specialist services. Any development of future services needs to take the entire system, that it will be embedded in, into account.**

**An EIP service would only work if all other components of the mental health service were staffed and operating well, otherwise bottlenecks would develop quite quickly to the detriment of this service."**

The overall mood was that intervention at an earlier stage would be an advantage for all parties involved: the individual, their family, healthcare systems and their community. In-patient services were thought to be overused, due to a lack of early intervention (despite best efforts.)

**"Police need to be aware when someone is seriously unwell basically insane that they need medical intervention not cells and court. Apologies but that is my experience on numerous occasions. A vulnerable adult database that can be accessed by all agencies if required and where any calls reports etc on said person be immediately dealt with as in most cases this is a matter of life and death. He was a poster child for immediate intervention still no one would listen."**

From the perspective of someone experiencing psychosis for the first time: they need access to mental health professionals quickly. Emergency services, helplines and NHS 24 resources are not able to meet their needs. They can protect from harm, but cannot diagnose or treat illness. A clear and reliable path in to services is needed both for their immediate safety and for their long-term mental health.

**"It prevents the need for admission. It safeguards. Reduces risk."**

It gives them an opportunity to have a more productive and equal relationship with the professionals who provide their care. If Early Intervention can be provided in the community, it can avoid the person having to be admitted to hospital. If they need to be admitted to hospital they have the chance of a shorter stay, with less chance of having to be detained. The economic benefits and improved treatment outcomes of Early Intervention Services are well documented. For the individual they mean:

- Less strain on personal relationships.
- Less exposure to risk when acutely unwell.
- Being able to play a more active role in their own recovery.
- More involvement in decisions that affect their lives
- A better understanding of their diagnosis and treatment.

**"The lack of support, the lack of understanding and the lack of psychiatrists... appeared to make it impossible to take him against his will even though his life was in danger. I had to write emails and make calls for a year until I was heard.**

**If he had early intervention he would most certainly not be facing numerous charges."**

## Early Intervention in Psychosis engagement project

### 3. RESPONDING TO DIAGNOSIS AND UNDERSTANDING IT

**“The lessening of stigma and fear: many people still feel when suffering psychosis they are a schizophrenic and classed as dangerous. This needs to be countered by supplying the facts about the illness.”**

At the point of diagnosis, people do not tend to realise how common psychosis is in Scotland. This is particularly true of people experiencing their first episode. The estimate that 3 in every 100 people will experience psychosis during their lifetime: highlights that this is a topic that is not as openly discussed as anxiety or depression. There is an opportunity to capitalise on the public awareness raising campaigns around mental health, to normalise the experience of psychosis. Newspapers and films were highlighted as sources of stigma and discrimination about both people who experience psychosis, and how mental health services are portrayed.

**“Dealing with psychosis at the earliest possible stage is of the utmost importance. I was diagnosed schizophrenic years after I first exhibited symptoms of the disease. We need to raise awareness around the illness and remove stigma so that people can be more open to early intervention.”**

People told us that they wished that they could have more information about psychosis, more detailed information about their diagnosis and signposting to other sources of advice and help. Information leaflets or resources were frequently unavailable in health settings, both for individuals and their families. This lack of resources has been compounded by Covid-19 as many leaflets and posters have been removed from GP practices, due to infection control. Many people felt receiving a diagnosis was a lonely and isolating experience. They did not learn until much later that they were not alone in their experiences. Commonly cited statistics could be a source of some solace and comfort. “Estimates are of 1600 new presentations of psychosis in Scotland a year.”

**“Active listening to their life experience and support in how to make life feel safer and feel more in control Understanding the role of statutory and third party supports Building up a broad support network and trust That you can have quality of life and live with voices Positive reinforcement and reassurance Reducing fear of yourself and those around you The sooner people are encouraged to access support without judgement the less likely they are to self medicate with alcohol and drugs or self harm.”**

In terms of being able to explain to another person what it was like to experience psychosis, a number of points arose. Both individuals and family members had clear ideas about the kinds of information they would have liked access to at the time. In terms of raising the profile of experiences of psychosis, this needs to be based on reality and be authentic. In order to ensure this, it was suggested such a resource should be co-produced with individuals with lived experience and their families. This information could be of value in informing the wider public and countering some of the negative publicity commonly encountered. But it could be of particular use for people seeking support to find the right source at the right time.

## Early Intervention in Psychosis engagement project

“More funding from the Scottish Government for NHS Mental health services. Less stigma attached to psychosis and more awareness that psychosis patients are still human beings. More health promotion of psychosis in patients and how colleagues/ acquaintances/ friends/ family can help to prevent psychosis/ recognise common pre psychosis symptoms.”

“A nationwide campaign about psychosis developing an understanding that it is more common than people think and raising levels of empathy and understanding removing fear on the part of the individual and the public at large and reducing stigma across the board Easy access to CBT and anxiety management programmes Information events for police/G.P. and community groups.”

Specific points people wished they'd known at the time:

- What is psychosis?
- Why might people not recognise their own symptoms?
- What is it like to hear voices?
- What does social withdrawal look like?
- What does paranoia look like? How does it feel?
- What are delusions? Realistic examples.
- The contrast: how psychosis presents for people experiencing a manic episode.
- Incidence: How many people per year? (2019 estimate was 1600 first episodes.)
- Prevalence: How many people are living with it right now?
- Who is likely to be affected? (Age range, gender, family history, ethnicity, life experiences, other known risk factors)
- The link between rapid access and improved outcomes.
- Severe and enduring nature, pressure on families and support services.
- Clear advice: **How to access services, and what to do next?**

The opportunity to connect with your peers and share your experiences was valued by many who took part in our discussion groups on Zoom. There was a strong desire to be able to continue these conversations. This was true both for people with lived experience and for their family and carers. For some people getting a diagnosis was important, validating and helpful in understanding themselves and the communities they lived in. For some the diagnosis itself carried with it a sense of identity: examples given were bipolar disorder, schizophrenia and post-partum psychosis. People who were diagnosed with schizophrenia often reported long delays (years or decades) to receive their diagnosis.

Changes of diagnosis were difficult for people to understand and a significant source of stress. For some people a new diagnosis meant a change of approach, or treatment. It often carried with it a less certain future, or a change of plan. A diagnosis of personality disorder often carried with it a change in attitude from services. For people with this diagnosis, treatment (for psychosis) was often harder to access in the future, if not impossible.

## Early Intervention in Psychosis engagement project

It was clear from the group discussions that psychosis frequently ran in families. Many people described having a parent, sibling, child or partner who had also experienced psychosis. This meant their impression of mental health services was based on previous life experience, rather than by media portrayals. Previous generations spoke about being shielded or protected from the full facts of their parents illness or treatment. The lack of open communication and the worry this generated, was agreed to be a focal point for improvement. As children, people saw and heard signs of their parent's distress; but were often not included in discussions about diagnosis, treatment or recovery. This meant that children remembered the things that were not discussed far longer than what was spoken about openly. It was easier to remember tears, shouting or ambulances during the night. It was harder to remember hope, recovery or reconciliation that followed. Worries about the future persisted for longer and were more difficult to deal with because they did not feel they could talk about them.

**“As a young child of someone who experienced psychosis and was hospitalised, I wanted to know what was happening. I saw and heard the signs of things going on in the house. It would have been better if I had been included, supported and understood.”**

For parents whose children had seen them in distress, there was a strong desire to include them in conversations about their mental health. For them to be well informed and to have the freedom to ask questions. Examples were given of advanced statements and Wellness Recovery Action Plans giving families the opportunity to prepare and plan for the future. There was a need for open dialogue within families; but also for children to grow up in a community where attitudes towards mental health are better informed and grounded in reality. Quite simply, it's easier to accept an ambulance coming to your home in the middle of the night if you know where you're loved one is being taken and why. It's easier to sleep at night if you know the person you care about is safe from harm and being looked after. Several people spoke about the relief of knowing the person they cared for was in hospital.

**“Specific to the patient: what is the intervention the patient needs? Ensuring the psychosis is recognised early on: developing a WRAP or safety plan to ensure the person is able to early identify triggers and support for any future episodes.”**

There came a point for several of the people we spoke with when they began to withdraw from professional support. This was not always intentional. The daily demands of keeping appointments and of taking medication, could be difficult to meet. Hearing voices and having inconsistent or incoherent thoughts were a barrier to many aspects of daily living. The fact that these difficulties are an inherent part of psychosis, needs to be accounted for by people delivering care. For people who failed to attend appointments, it was often difficult for them to get back in touch with services.

## Early Intervention in Psychosis engagement project

### 4. MEDICATION AND TREATMENT

Within the groups we engaged there were a number of different diagnoses, and there was more difference of opinion than with some of the other discussion themes. Overall what stood out was that medication was frequently seen as, “*The Treatment.*” As opposed to a component of an overall care plan, an intermediate step, or an option.

**“Have a peer support worker with lived experience of psychosis on the staff team, empathy and understanding makes a huge difference and I would have been more likely to trust the person I was speaking to. Re early intervention I would like to see a self-management training course e.g. a WRAP course facilitated by people with lived experience of psychosis. I believe that taking part in such a course where everyone has experienced psychosis (not diagnosis specific) would be most beneficial. I also think that setting up a peer support group with people who had taken part in the course would help make it easier for people to stay on track. After taking part in a self management course I was able to reduce my medication and use an anti-psychotic PRN. I managed that with a lot of support from peers and health professionals but being given the opportunity to do that has made a huge difference to how I feel both physically and emotionally.”**

At the point of accessing services for the first time, many people were so unwell that they were unable to make a clear and informed choice about taking medication. Medication was always rapidly available. Other forms of support (psychology, OT & social work) often required long waiting lists, if they were available at all. There was a need for advice about self-management, self-care and lifestyle advice for people with psychosis.

**“Professionals need to be aware of the highest executive functioning level of those experiencing psychosis to ensure there is no undermining of their capabilities. Challenge of only seeing people in crisis situations or when really unwell.”**

Some people used alcohol or drugs before seeking help for their mental health. Some acknowledged it as a risk factor for their first episode of psychosis. Others began to use drugs or alcohol in order to self-manage symptoms such as hearing voices or mood swings. It wasn't always clear which arrived first: symptoms of psychosis, or use of alcohol / drugs. This meant some people being prescribed medication while still using alcohol or drugs. For others it meant losing a coping strategy as they tried to curb their use, without proper support.

**“Training opportunities for staff should also include warning against overuse of or overreliance on psychotropic medications.”**

Use of alcohol or drugs was frequently the, “Elephant in the room.” It was a difficult topic for people to talk about within mental health services, for fear of being denied treatment or discharged altogether. It frequently impacted on their medication and treatment. It took time and trust for people to talk about the underlying causes. (In an acute mental health setting, time is short.) Trauma and adverse childhood experiences were frequently mentioned. The result was that treatment often had to start before the causes were talked about, or understood.

## Early Intervention in Psychosis engagement project

A significant number of people we spoke to had never been offered an appointment for clinical psychology so were unaware of any potential benefits. Many people felt pressured or coerced to take medication because they were acutely unwell and alternatives were not as readily available.

People wanted clear information about the medications they had been prescribed. They wanted to know:

- How their medications worked.
- What specific symptoms, or condition they were being prescribed for.
- Why the medication had been chosen for them.
- How long it was expected for medication to start working.
- Any time frame for the treatment to be reviewed.
- If they would be taking the medication for the rest of their life.
- The possibility that medications might not work (treatment resistance.)
- Prior warning for severe or life threatening side-effects and who to contact.

Some people were prescribed medication at such high doses that their medication became an impairment itself. It was common for people to have to take combinations of different medications (for example, two different antipsychotics and a mood stabiliser.) Several people spoke about taking clozapine, or denzapine, after other medications had been unsuccessful.

**“There is a pill for every ill. I was prescribed medication for side effects, caused by risperidone. I worried that I was just taking more and more medication. Eventually, I was able to change to flupentixol. Now that’s all I take.”**

Finding the right medication and the right dosage at the right time was a significant milestone for a number of people. However, it was often a long process of trial and error to arrive at this point. (Particularly true for antipsychotics.) Many people felt their concerns about effectiveness and side-effects were not acted upon early enough. This meant they felt left out of the decision-making process. People who had a clear understanding of the overall benefits, risks and side-effects, were more likely to take their medication and to tolerate side-effects. People wanted clarity about how long their medications needed to be taken for in the long-term. They also wanted to be able to compare the risks of continuing to take medication, weighed up against the risk of tapering off medication in a controlled way.

**“What I’m looking for is informed self-management. How to balance the side effects from medication against risk of relapse. From a service-user perspective I would want to see proof of concept.”**

On the other hand, a significant number of people did suddenly stop taking their medication at some point. Without clear advice, guidance or support this often led to them becoming unwell again. Many people felt frustrated that the side-effects they experienced were not being listened to, acknowledged or acted upon. One particular point of difficulty was for people who were moving to a new area. The process of getting a new consultant, registering with a new GP often resulted in interruption to their care and supply of medication. Transitions of any sort (be they moving house, staff changing or leaving) often meant there was no coherent message about

## Early Intervention in Psychosis engagement project

medication available. People were often, “parked,” on medication without a clear plan either communicated to them, or recorded in their clinical notes.

**“Being stranded on depot medication for forty years as I have been is not the answer. As I say we need Hearing Voices Groups which are really helpful, Creative Writing Groups which are really stimulating, Psychology Courses which help people with psychosis to recalibrate their lives. “**

This often resulted in new staff lacking confidence, or authority, to make decisions about changing dosage or managing side-effects. Lack of continuity and clear communication often meant queries or changes had to be referred back to a more senior member of staff, who may never have met the patient. The end result was that medications were continued for longer, at higher dosages and in the presence of significant side effects.

Families and carers often felt poorly informed about what medication should be taken, how often and what the side effects might be. It was often a difficult topic to discuss. They frequently worried if medication was being taken, or not. For people who suffered the most severe side-effects, such as seizures or heart problems: family members often had to seek help for them. They did not always know which medications were being taken, or the dosage. They had not received prior warning of the risks involved of taking the medication, so did not always realise that the current problem was a known side-effect.

Some people reported that they had been unable to tolerate medication, but had succeeded in finding other ways of coping and self-managing their symptoms.

**“Some people prefer not to use medication and want that respected.”**

Three further points arose from this:

The first being that self-management strategies and sharing of lived experience were key in allowing people to function at a high level in daily life. This insight and ability often came as a result of the individual carrying out their own research and having the initiative to seek out community-led resources.

The second point was that, for some people, the side-effects of medication outweighed the potential benefits. This underlined the point that not only was recovery from psychosis and the methods employed, unique to the individual. But also that the balance of benefits against side-effects were fluid and could change over time. It was better for individuals, and their families to arrive at this conclusion in partnership and with professional guidance and the support of services. Some people were able to taper off medication in a controlled and supported way. Others were able to reduce the dosage and lead an improved quality of life, with fewer side effects.

The third point was that individuals and their families were the ultimate judge of the relative successes of treatment. Many of the breakthroughs for individuals were arrived at either without the provision of statutory services, or in partnership with them. Examples provided were peer

## Early Intervention in Psychosis engagement project

support groups, peer support training, hearing voices groups, volunteering, collective advocacy groups and self-management training.

These resources were of great value to the individual and the successes they brought with them, could be readily captured by outcome measures that focussed on the personal outcomes of the individual. Indeed the ability to seek out solutions, to take supported risks, to make informed choices and to develop a level of independence from NHS services were some of the most highly prized outcomes from treatment. It was felt that NHS services did not always understand or capture this. There was a clear need for services to employ outcome measures that recognised what was of greatest importance for that individual. But also to have a greater respect and awareness of the experience of recovery for the individual, the assets employed to achieve this and the motivation and resourcefulness needed to seek them out. There is an opportunity for NHS services to work more in partnership with these community assets.

By focussing more on all of the resources available to the individual, and on the needs and values they meet NHS services can better understand and define their own role. By focussing excessively on service-based measures and medication: some NHS services sold themselves short. They did not always recognise or understand the progress an individual had made. Nor did they fully acknowledge their role in helping to achieve them.

**“People to be kinder to me and treat me with compassion. Stop saying what I am experiencing isn't real. Actual therapy and someone to help rather than only medication “**

**“People with Psychosis need a lot of reassurance and comfort. They also need to see sign of life or life lines a reason to go for treatment. You need to Person centre planning focusing on the patient goals.”**

**“People believing in me and having hope Addressing the social factors I was experiencing - having my own home, money etc. Whilst increasing the services around me was seen as the safe way forward, it was actually debilitating. I needed to have my own space/home, make mistakes, take risks, build relationships rather than have a life that revolved around services and staff members as my main social contact. Knowing that my experiences were not unusual and that there was hope. Medication could be a tool rather than the only thing -just need to get the combination of meds rights took the focus away from developing a personal understanding of what I was experiencing, Services been aware of the self fulling messages they give out both explicitly and implicitly - people ned to be ware that recovery is possible and witness it in others i.e. peer workers and other team members owning their own experiences. Collaboration and co-production approaches as the main relational approaches. I was very withdrawn and full of mistrust - investment in time and relationship building much earlier would have helped.”**

## Early Intervention in Psychosis engagement project

### 5. A SERVICE THAT MEETS INDIVIDUAL NEEDS

**“Services don’t always realise how much people struggle with daily tasks for independent living eg cooking, paying bills, finances, self-care, taking and ordering medication.”**

There was an overall feeling that care was planned, delivered and structured according to the needs of the service, rather than those of the individual. One clear example of this was the dramatic shift people reported who experienced a change of diagnosis. In these cases the individual did not suddenly change: yet the service around them shifted markedly. The individual did not suddenly present the service with a new catalogue of needs; nor did they shed a list of previous requirements. Yet the services responded as though they were now catering for a different person, based on a list of assumptions tied to their new diagnosis. Several people felt that this was evidence of stigma and discrimination, on the basis of diagnosis.

**“Looking at my experiences through a different lens and understanding the chaos in my head as a natural and protective response to adversity and trauma as well as more understanding about neuro-diversity and sensory processing which can underlie so called psychotic experiences.”**

Within the group discussions, people could easily relate to each others’ factors and triggers, that led to a first episode of psychosis. There were a number of life experiences that frequently combined, irrespective of the individual’s diagnosis:

- Adverse childhood experiences (accidental or non-accidental)
- Bereavement
- Childbirth
- Family history (social and genetic)
- High academic or professional achievement
- Intense motivation, or drive to succeed (perceived or self-imposed pressure)
- Isolation
- Lack of another person to confide in (amplifies other factors)
- Leaving home for the first time
- Moving to a new area, or country
- Parenthood
- Relationship difficulties
- Serious illness or infection (kidney and urinary tract infections were mentioned by four individuals)
- Stress
- Trauma

**“Reduce stigma attached to the type of experiences that get labelled as psychosis and greater understanding of social context rather than just medical model framework for understanding**

## Early Intervention in Psychosis engagement project

**such experiences. More choice over type of intervention and opportunities to talk about voices and other experiences.”**

People needed to talk about their experiences and understand what had caused them. They did not always have that opportunity until much later; some did not have the chance at all. Gaining this understanding, would give people an opportunity to lead their lives in a meaningful way that did not recreate the circumstances that provoked their first episode. This notion, *of history not repeating itself*, was important for both the individual and for their families. Clearly there are genes that predispose family members to psychosis. However there are also attitudes, behaviours, beliefs, values, relationship styles and means of communication that are modifiable in ways that genes are not.

**“Some practitioners are helpful when they can acknowledge the struggle and can relate the courage it took to sought help. That it’s private thoughts that are very embarrassing and difficult to express.”**

Put simply, people who could relate to their healthcare workers, could involve their immediate family more readily in their care and treatment. If they had faith and trust in the people providing their care, then this gave them the opportunity to explain to their family what was happening with their care and treatment. When hospital stays were planned and organised it gave their family reassurance that their care was adequate. This meant that for the individual’s immediate family their diagnosis, care and treatment could be talked about and understood. This meant a life lived intentionally, rather than dictated by abrupt or unexpected admissions to hospital. Identifying what makes an individual well, gives their children the best chance of staying well. People who spoke to us accepted that their children could not be immunised or protected from experiencing psychosis themselves in the future. However, they were able to ensure that their children could be well-informed and included in discussions which had an effect on their lives. A key part of this was being free to discuss mental health, able to ask questions and valued for their insight and opinions.

**“Knowing who to turn to is the first step and feeling comfortable (or reasonably) so putting your trust in a total stranger. “**

The more people were able to express what had made them unwell, the better they could prepare and plan for the future. Being able to communicate openly and freely as a family, meant people had more motivation to pursue recovery. Being listened to and clearly understood was key in how people presented themselves to services. People who felt their input was valued were more likely to confide in and trust the people providing their care. When people began to tell their story it did not always come out completely and coherently the first time. This highlights the importance of an attitude of listening as the most important things were not always spoken about first. The most urgent information tended to come first. If this was picked up and acted upon it gave people a safe space to talk about more long-standing issues, or more delicate subjects.

**“In my professional experience working in the addiction sector, often service users struggled to get the right input with mental health issues (including psychosis) if they had an active addiction. More dual diagnosis/integration of addiction and mental health services needed to support this**

## Early Intervention in Psychosis engagement project

**vulnerable population. In personal experience, having experienced a transient psychotic episode in the days after giving birth, I was very fortunate that a nurse on the maternity ward picked up that I was acting strangely and intervened. My condition was exacerbated by severe sleep deprivation and support was put in place for me to get an uninterrupted nights sleep, which made all the difference and possibly prevented more severe issues developing."**

People who did not feel listened to, or respected, initially were less likely to open up further down the line. Some of the topics that were difficult to talk about were important in terms of diagnosis, treatment and ongoing management. A lot of the reluctance to confide in psychiatrists and other mental health professionals was linked directly to the fear of being treated differently after they had made a disclosure. The level of reluctance to talk was related to the level of discrimination that they expected to face as a direct consequence. There was a clear tiered system in terms of the level of trust someone needed to have in order to broach a difficult subject. In ascending order:

**1. Embarrassed (Difficult to talk about)**

Past medical history, financial issues, relationship difficulties, parenting and caring responsibilities.

**2. Afraid (More difficult to talk about – risk of being refused healthcare/discharged)**

Bereavement, housing insecurity, victimisation at work, negative prior experiences of healthcare and past use of alcohol or substances.

**3. Guilt or inadequacy (Very difficult to talk about – likely to be blamed by healthcare)**

Current use of illegal substances, traumatic childhood experiences, domestic abuse, being a victim of coercion/control, witnessing violent and/or sexual crimes.

**4. Shame (Extremely difficult to talk about – may view healthcare worker as complicit)**

Being a victim of sexual or violent crime, modern slavery, human trafficking or hate crimes.

**5. Mortal fear**

**(May not be possible to talk about – may fear healthcare worker is going to hurt them)**

**(May refuse to enter hospital – as likely to fear other patients)**

**(May not seek out care themselves)**

**(May not have a *safe space* for telephone or virtual appointments.)**

Victim of any of the serious crimes listed above *and still under direct threat from the perpetrator.* (eg attacker released, never convicted, close by or cohabiting)

This tiered scale is fundamentally different to measures of trauma – because it directly relates to how the person expects to be viewed and treated by their healthcare professional.

**"In my own personal case this was evidenced by a nurse intervening when she noticed my behaviour had changed (I had become very withdrawn and depressed and while I wasn't verbalising much I was experiencing hallucinations which were telling me to take my own life). Professionals building a good relationship with clients/service users/patients, and being aware of their normal presentation. being curious/supportive and exploratory if these patterns change.**

## Early Intervention in Psychosis engagement project

**Building trust and collaboration so people feel able to disclose any frightening and disturbing experiences (in my case I was deeply ashamed of myself during the experience and initially convinced that the nurse was disgusted with me, which she was able to overcome with empathy and supportive dialogue). “**

Examples given included:

- being discharged to a voluntary alcohol counsellor (for disclosing alcohol use.)
- being discharged from psychiatrist due to self-harm.
- believing a chemical restraint was being used by nursing staff to facilitate a sexual assault.

**“More support for my loved ones especially my children. More positive examples of psychosis in the media, social media and entertainment - they always focus on really negative extreme examples a good example of this is the recent Joker film. A good campaign de-mystifying psychosis and voices explaining how they are not always harmful that people can live day to day a normal life.**

**Education about mental health from a young age in schools ( really important) . Access quickly to a psychologist and more than 6 sessions! Specialist hospitals that only deal with mental health - in Fife the hospitals have the patients with addictions with the patients with psychosis . Know they're can be a cross over but in my experience they're is always a divide.**

**It's very different treatment for say an alcoholic that a person with a severe psychosis - even staff find this difficult to deal with. I was offered heroin by a girl who said it would take my voices away. One patient I knew a young boy believed her and let her inject him. This is really important it's not a judgement at all but they're should be specialist ward for addicts and mentally ill it's really difficult for staff and patients. They're had in my experience been a lots of bullying from recovered addicts. More protection for woman in wards.”**

**"Staff secondment/ redeployment /absence / holidays/ career breaks have all resulted in gaps in my daughter's care. It just means the staff are not there for his appointments, when he needs them. It's not always the staff's fault, but no one seems to realise that they are not there and not seeing patients. There is no one to fill in for them and it takes weeks to get another appointment from them."**

Therefore, a key need for people to trust a healthcare worker is to know that what they disclose cannot be used against them, to discharge them from care. It is important to listen and to realise that the causes of someone's psychosis may not all have happened recently, or be talked about in the first few meetings. These fears cannot be dismissed as irrational in cases where they are based on actual life events.

**“Being believed and taken seriously! I was tormented by a voice that was telling me to kill someone and another about cleansing sin by shedding blood - I was very distressed. I was told that if I acted on it I would end up in the state hospital - no working with me to make sense of the voices I was hearing and why the content was so disturbing. Having people who understood the link between trauma and psychosis - joining the dots!”**

## Early Intervention in Psychosis engagement project

There was a clear need to understand the individual's daily life and the demands they faced:

- The present: work, study, parenting, caring responsibilities, finances, housing, stressors etc.
- The past: development, childhood, ACEs, trauma, family history (social & genetic.)
- The future: immediate priorities, motivation, interest and future goals.

Good physical and mental health was an immediate priority, for a number of people experiencing their first episode of psychosis. Many people had more than one mental health diagnosis. Some of the examples were anxiety, depression, post-traumatic stress disorder. And bipolar disorder (without psychosis.) General health conditions were also common. For both physical and mental health conditions, these often needed a degree of self-management from the individual. It also often meant that people had to attend appointments and take medication in addition to receiving care and treatment for their mental health.

People may have other significant health needs. Examples given were breast cancer, cystitis, kidney infection, hyperthyroidism and rheumatoid arthritis. These meant having to access other NHS services whilst also accessing mental health services. The point was raised that receiving care for cancer was a much better experience ("night and day") than being treated for a mental health condition. (Being listened to, being respected, clear communication, receiving effective treatment and having their family included when planning care.)

There were several reports of a first episode of psychosis occurring as a result of other medical treatment:

- Withdrawal from morphine following a hip replacement.
- Whilst taking ciprofloxacin for kidney infection.
- Whilst taking anti-depressants (fluoxetine, escitalopram and imipramine were named.)
- After starting prednisalone for rheumatoid arthritis.

## Early Intervention in Psychosis engagement project

### 6. THE TRIANGLE OF CARE

Before beginning to talk about the vital role that partners, family members and unpaid carers provide; it has to be made clear to services that not everyone is fortunate enough to have this support. People who live alone, or do not have support from family may need additional support:

**“Not all people have a safety net of family and friends – there should be points of contact for Early Intervention. “**

**“Groups of like minded people will help and support each other. By not co-signing it, but sharing experience with each other. To help each other see it for what it is.”**

**“More support groups with other patients to let them see there is life after a diagnosis and they are not alone. Encouragement to make a good life for themselves.”**

**“Peer support for these people as they are at risk of becoming some of the most marginalised in society. “**

The ‘Triangle of Care’ is a working collaboration, or “therapeutic alliance” between the service user, professional and carer that promotes safety, supports recovery and sustains well-being.

It is based on six principles:

1. Carers and the essential role they play should be identified at first contact with services or as soon as possible thereafter.
2. Staff should be aware of carers and trained to engage with carers more effectively.
3. Policies and protocols should be in place to ensure confidentiality and improve information sharing with carers. This is of particular relevance in psychosis, paranoia and suspicion are to be expected: trust is key.
4. Defined roles (Carer link workers), responsible for carers should be in place.
5. Carers should be “introduced” to the service and provided with a range of information.
6. A range of carer support services should be available to offer or signpost carers to.

The overall feeling was that mental health professionals are restricted in how they can communicate with family members and carers. Many parents, partners and family members had significant concerns about the mental health and safety of their loved ones. It was frequently the case that both the first signs of distress and the first attempts to seek support were made by others. Family members at this stage were not asking for any personal information: only for access to help and safety for the person they loved. They are not asking for information in return, only trying to provide information.

## Early Intervention in Psychosis engagement project

“Easy and quick access - GP process can be prolonged due to understanding what a person is experiencing and picking up clues earlier before person reaches a crisis. Much quicker referral into MH services -often takes too long (weeks, if not months for appointment unless in crisis and use of MH Act). Families and close friends being believed when they approach services with concerns though being mindful of dynamics where the individual may be scapegoated as 'the problem' and where abuse/bullying could be present.

Meeting people initially in their own environments - take learning from Open Dialogue approaches. Too many people focus here on inpatient services, for many that is only a part of their interaction with services, if at all. An early intervention service would seek to work with people in their own environments as much as possible. Having information in different formats including animations and films. Info co-produced with people with lived experience The physical environment of services to be bright, welcoming and clean. You are personally welcomed on arrival -doesn't take much effort but often you are ignored as you wait at a reception desk. All staff introduce themselves and their role, The emotional environment is one that is welcoming, sensitive and positive - trauma informed and responsive People feel valued for their experiences and knowledge of self/loved ones. Sense of collaboration and belief in recovery.”

“It was difficult to sit back and watch, feel helpless.”

“I was not listened to in the early stages. It was initially classed as depression, attended GP with several family members and not listened to until a crisis happened. My other adult child, the GP did listen and agreed they needed to investigate.”

The context of this engagement was to find ways to increase and speed up access to services. Psychosis is a condition that responds best to prompt treatment. Two areas that people's families sought to improve were:

- Training for frontline staff about how to recognise signs and symptoms of psychosis.
- A rapid triage system for people who seek support and for family members with concerns.

“Being able to have a person to contact when the person you care for can't and are unable to get help for themselves.”

“More awareness of symptoms in professionals eg GPs and social workers. My concerns about my son were dismissed as anxiety.”

“My experience is that the GP and mental health services do not respond quickly enough and this results in a constant decline in the situation resulting in a truly tortuous experience for the person living with the psychosis and an increasingly stressful/distressing situation for care team and family. This causes a huge decrease in the physical safety of all people involved. This poses a safeguarding concern. “

“Important that initial GP consultations are taken seriously and involve family members if possible. I think often GP's may 'fob people off' in the middle of busy surgeries. Perhaps improving mental health provision in health centres would help.”

## Early Intervention in Psychosis engagement project

Confidentiality often limits services from being able to provide information to families about the person who is under their care. This is a disadvantage to the individual, as it means their families can only seek out generic advice about how to provide care. They cannot receive advice that is tailored to the individual needs of the person they are providing that care to. Receiving a leaflet about a psychiatric diagnosis (eg schizophrenia or first episode psychosis) is useful up to a point. However it cannot provide any specific information about what that individual needs. Reference was made to the value of Wellness Recovery Action Plans and to the use of advance statements.

These provided some practical information to members of the family. Information that could include advice about what to do in times of need. They gave mores specific information about:

- The kind of daily activities that are helpful in maintaining health
- What to do to self-manage symptoms
- The medications and treatment that had already helped
- Triggers and warning signs that could be acted on
- Contact details for health professionals
- Emergency contact details

**“What would have helped? Family/friends /carers being listened to and communicated with by the professionals (NHS)”**

**“It is important to have a plan and possibly an advanced statement whenever possible. Also it would be great to develop a relationship with a MH professional who can stay in touch with you and visit you during your admissions to the hospital, as well as a MH advocate worker who would represent your views or help you to express your needs while being unwell. As mentioned before, I would like to have someone from the team at the hospital explain to me (once I was able to understand which actually happened within 48 hours after admission on a first occasion and 24h on the second occasion) what has happened and why was I there and what will happen next.”**

**“The word 'early' is vital and care should be immediate, person-centred, individualised, multidisciplinary, inpatient or outpatient as required with excellent communications within the services, with the person experiencing symptoms and with immediate unpaid carers. Communication is vital and the services should include the unpaid carers as they will often be able to provide invaluable information/insight which could help to inform the care pathway. Our experiences: Our cared-for's signs & symptoms were not recognised by him, or us his family or friends or his GP despite what we now know were major symptoms becoming worse. Thankfully, the police recognised a young man in distress and he had to be admitted to hospital for a lengthy inpatient stay (13 weeks) from where he was discharged prematurely despite being very unwell/exhibiting many signs & symptoms. NB There must be sufficient bed capacity in mental health hospitals as there are times when only inpatient care will make a difference.**

The point was repeatedly made that the NHS, as a system, needs to be able to work with families. Family, friends and carers are relied upon by the NHS to provide care, but often not communicated

## Early Intervention in Psychosis engagement project

with clearly or effectively. The entire mental health system is under-staffed and overstretched, not just wards & specialist services. However families and carers they are often overstretched too. Many carers are unpaid and do not have the same clearly defined roles and hours that NHS staff have. An assumption is often made when someone is discharged that family, friends and carers are able to provide care. Psychosis could be an isolating experience for both the individual and for their family. Interruptions to education, work and family roles were significant. Parents fear for the lives of their children if they are no longer there (or able to provide housing, care and support.)

**“That they get help as soon as possible, that carers get the information they need and if carers would like to be involved in helping, that they can.”**

**“Having someone there to help us as parents of a 27 year old when we felt helpless because the patient was an adult. We were expected to get the psychotic persons permission and at that time clearly could not seek help for himself. “**

## Early Intervention in Psychosis engagement project

### RELATED ACTION POINTS – WHAT ELSE DO POLICY MAKERS NEED TO ADDRESS?

The people we engaged highlighted a number of broader issues. Many of these issues are on the agenda of the United Kingdom and Scottish Government, respectively. They are listed and briefly discussed in terms of the relevance they have for people with lived experience, their families and carers. Reforms in these areas impacts who will experience psychosis in the future, what will be in place to support them and how accessible that support will be. For early intervention to work effectively, there are some issues to address outwith the control and remit of NHS boards. These systemic and societal issues include:

- Health inequalities
- Inequalities on the basis of protected characteristics
- Access and entitlement to benefits, advice and advocacy for individuals their families, carers and dependents.
- Recovery and transition from the Covid-19 pandemic.
- Individual access and ability to use digital communication methods.
- Individual mobility, regional access to transport and restrictions.
- Understanding of mental health and access to care in the criminal justice system.
- Levels of use and availability of alcohol and drugs in the community.
- Controlled drugs are classified according to the overall harm they cause (addiction, overdose and deaths.) Controlled drugs that cause problems for people with psychosis (stimulants, hallucinogens, cannabis and spice) are not as tightly controlled.

**“User-informed services are so powerful. Input from services users will generate more effective, valuable and efficient services. An additional positive is to create value from these painful experiences for the service users. This allows people like me to use our knowledge to contribute to our communities. This is part of my healing, builds my confidence, repairs my damaged self-esteem. I get to feel like a valuable member of society again.”**

**“Mental health care should take account of social and political contexts (poverty, inequality, loneliness and isolation) that contribute to a high prevalence of poor mental health and distress. Psychosocial and other social interventions are crucial for mental health recovery. Third sector services and those offering peer support can provide additional resource to step up support.”**

**"I don't get involved with what I think of as "the political or administrative side" of Mental Health issues"**

**"People are sick to death of being asked."**

**“Thank you - I know funding is limited and I value this opportunity to feed into the processes and the efforts at least to centre voices of lived experience, even if there are limited options for improving the service itself. “**

## Early Intervention in Psychosis engagement project

**“Look after staff; off sick apparently, not Covid but stress?! Any planning needs to ensure post code fairness,,,,,not merely the likes of Edinburgh!”**

**“More investment into resourcing and expanding mental health services is needed sooner rather than later. Professionals need to listen to lay-people better. It is too easy to make sweeping statements and totally disregard the lived experiences of the people. It was my experience that GP's are not necessarily well educated/resourced and/or do not have the interest and/or capacity to deal with such situations. It is understandable as they have an enormous remit to deal with. It is easy for lay-people and social care professionals to become disillusioned with Health Care Services. Better partnership working is needed.”**

**“Lives have been and are being ruined because the mental health service was not fit for purpose before the pandemic and I suspect it is worse now.”**

There are *fundamental and strategic* issues within the broader structure of the NHS. Any implementation of Early Intervention in Psychosis service needs to take in to account:

- Accessibility of NHS services to people from black and minority ethnic communities.
- Access and availability of healthcare to remote and rural communities
- Overall capacity and demand on the NHS, particularly frontline services.
- General mental health service availability, capacity, effectiveness and accountability.
- Staff recruitment, training, retention, welfare and safety.
- Confidentiality and GDPR issues that restrict staff communicating and working with family members.
- Confidentiality and GDPR issues that restrict staff carrying out engagement work with individuals and family members, who use their services.
- Access to support, and stigma and discrimination of people who use alcohol and drugs.
- Availability of information about psychosis, public awareness, public dialogue and media discourse.
- The default power position of the NHS on the ladder of participation and engagement: People with psychosis are informed they need an E.I.P. service and consulted on what is currently available.

The themes discussed and desired action points, which people with lived experience have requested, are a direct consequence of the society in which we live. There are social and environmental factors that contribute to an individual experiencing psychosis for the first time. There are social and environmental factors that influence demand on the NHS and on mental health services specifically. Implementing rapid, effective early intervention needs to take in to account the regional and national policies that govern the populations they serve. How successful early intervention can be in practice, will depend on how well the NHS is functioning as a whole.

## Early Intervention in Psychosis engagement project

### SUMMARY OF ACTION POINTS – WHAT DO POLICY MAKERS NEED TO ADDRESS?

#### For people experiencing a first episode of psychosis:

The most important issue is of being listened to, and being taken seriously regarding the experience of psychosis. Encouragement and support is vital as is a clear pathway of referral to services at a point which avoid crisis. In such situations carers and families need to be listened to as these can often be the first to notice changes in someone's behaviour, appearance, or manner.

**“How you are treated both medically, and as an individual is very much dependent on 'who, how much experience/training and how good' that health professional is in dealing with mental health. It just takes one person to afford you the time and effort to make the difference to someone's life. This may then stop the revolving door effect as I've heard it described. “**

Health and Social Care Partnerships need to ensure that frontline staff have adequate training and awareness of psychosis. This should highlight awareness of symptoms from individuals as well as signs noticed by family and carer's. First points of contact include: call handlers, GP practice staff, 111 and 999 call operators.

GPs and nurse practitioners need specialist training to triage, identify and rapidly refer people when psychosis is suspected. It was strongly suggested that there should be a Community Psychiatric Nurse (CPN) within each GP practice:

- This would begin a clear pathway for people with first episode psychosis.
- It should also ensure people with other significant mental health needs also receive the care they need.

People with lived experience need clear, concise information about first episode psychosis. They need points of contact with clearly defined roles. An example might be a simple diagram of the pathway with contacts for appointments, their caseworker and out of hours / crisis.

**“Having a named professional with knowledge of the individual, who you can trust.”**

Where medication is prescribed people and their families need accurate information that includes both medication benefits and side-effects. When side-effects are experienced these should be acknowledged in the context of overall risk vs reward. (For example the Glasgow Anti-psychotic Side-effect Scale.)

People with lived experience (including their families and carers) should be involved in staff training and the development of new services and pathways. There is a wealth of knowledge and experience in third sector organisations (for example collective advocacy groups) which should be drawn on. There is also a clear need for services to work collaboratively with community assets to ensure people with lived experience have access to social activities, community resources and meaningful activities that meet their individual needs.

## Early Intervention in Psychosis engagement project

### For family, carers and supporters of people experiencing a first episode of psychosis:

For those providing care and support to someone experiencing first episode psychosis it is essential that they be included as equal partners in the delivery of care to the person they care for.

**“The Triangle of Care must not merely be a document on a shelf but enacted meaningfully. Unpaid carers, family members or friends often have 24/7 responsibility for the person experiencing symptoms and this must be recognised and valued!”**

At the point of accessing services, professionals need to ensure that information is taken from people who know the individual best. Where possible this can be best achieved by a three way conversation including the individual, their family member and the mental health professional.

Wards and community mental health teams need to ensure good, clear, concise communication with family members, carers and supporters at points of admission/transition and discharge.

It is a duty on health boards under Carers (Scotland) Act to involve carers, as much as is practicable, in discharge planning of patients.

Families and carers need education, support and specific guidance about the individual needs of the person they care for. This information can only come from the individuals mental health professionals. If consent does not allow this, they should ensure generic resources are readily available and communicate with family members as much as is possible to achieve this.

Families and carers need access to Adult Carer Support Plans if they require more support and access to individual support/respite if needed. Services for people with psychosis should work collaboratively with organisations that can provide specialist information, support and advocacy when it is required.

Family and carers need clear information about who to contact and how fast if the person they care for is becoming unwell again. (One example where this worked well was Enhanced Access Pathway in Grampian.)

## Early Intervention in Psychosis engagement project

### For services for people experiencing a first episode of psychosis:

The key elements of care that services need to provide for someone experiencing a first episode of psychosis are:

1. To actively collect data on the numbers of people presenting to their service.
2. To employ a human rights based approach to the delivery of services.
3. To provide person-centred care that is structured around the needs of the individual.
4. To involve the individual's family actively in care, treatment and therapy.
5. To work collaboratively in partnership with third sector organisations that benefit both the individuals needs and those of their family.
6. To pilot new and innovative approaches in response to emerging research evidence.
7. To be accessible and to accept referrals from a range of sources.
8. To work productively with referrals to ensure that people with first episode psychosis are identified and contacted.
9. To have a key worker as a central point of contact who knows and understands the individual.
10. To be easily contacted and be able to respond quickly.
11. To provide information and communicate well.
12. To provide continuity of care (ensure messages are passed on, case notes are read).
13. To visit and understand the individuals home environment
14. Timely access to psychology, OT, peer support.
15. To use a range of treatment methods: to not rely excessively/unnecessarily on medication.
16. To use community access / home setting where possible (ie use hospital only if needed)
17. To be able to provide intensive support to avoid unnecessary hospitalisation.
18. To collaborate with service users & carers in design / development / improvement
19. To employ and build on the learning from accelerator site boards into how meaningful engagement can be achieved within the allowed frameworks of confidentiality and GDPR compliance.
20. To identify and proactively manage alcohol / substance use. People who experience psychosis are uniquely vulnerable to the negative effects of tobacco, alcohol and psychoactive substances (legal, illegal and prescribed.)
21. To identify unmet needs that might impact on psychosis. eg Post Traumatic Stress Disorder, autistic spectrum conditions, ADHD.

## Early Intervention in Psychosis engagement project

### CONCLUSION – WHAT DOES THIS ALL MEAN?

There is a desire for services for people with first episode psychosis to be developed and improved across Scotland. For each region there are issues around the number of people they expect to see each year, and this will effect the model of delivery of intervention in each health board area. It is therefore of great importance that the number of people who access services are accurately recorded and that this data is analysed and published.

To make early intervention possible there is a need for information that highlights the issues for:

- The general public – there needs to be awareness of psychosis as a public health issue. This needs to target schools, young adults and parents.
- Frontline health workers need additional information to know how to detect and refer.
- Individuals and their families need in depth and detailed information on diagnosis, treatment, including about services themselves and support available.
- Families need information and support that meets their needs as individuals, and as carers.

The word, “listen,” is perhaps the one word that I have heard spoken most often. How services are delivered is every bit as important as what they are delivering. The attitude of the listener is not to be under-estimated (and this is likely to be affected by the size of their caseload.) Listening needs to be active, and understanding and validation are key.

**“In my opinion compassion, empathy and respect should be central to all care provided. In therapeutic work it is recognised that the therapeutic relationship is often the central vehicle for change. I've met some outstanding mental health staff in both personal and professional setting, but also have met staff who still have stigma/judgement about certain mental health conditions, and their attitude can affect the quality of care they provide. “**

People presenting with psychosis need their experiences to be heard, understood and root causes identified and addressed. There needs to be a focus on developing informed self-management and coping with and understanding symptoms. Care for people with psychosis needs to be person-centred and focus on personal outcomes. There needs to be a combination of treatment methods that include psychological and family interventions as well as social activities, peer support, volunteering and access to education and / or employment.

Human rights are a central issue for people who experience psychosis and for their families and carers. Services need to focus on the needs and rights of the people they deliver services to. Development of services needs to place people with lived experience and their families at the heart. There needs to be a willingness to engage in partnership working with wider stakeholders to facilitate user-led access to all available resources.

**“User-informed services are so powerful. Input from services users will generate more effective, valuable and efficient services. An additional positive is to create value from these painful experiences for the service users. This allows people like me to use our knowledge to contribute to our communities. This is part of my healing, builds my confidence, repairs my damaged self-esteem. I get to feel like a valuable member of society again.”**

## Early Intervention in Psychosis engagement project

“EVERYONE needs to know more about the symptoms of mental illness in general, and psychosis in particular. Early intervention can only happen if there is early recognition by the person experiencing symptoms.

Family, friends, work colleagues, social workers, police, A&E Departments, GPs & GP receptionists should all be able to refer immediately. There needs to be a timeous route to an early intervention service: whatever that looks like, fairly locally. Signposting to early intervention should be readily available and immediately accessible. Early recognition would help to enable early intervention.”

“No door is the wrong door. With individuals and families being linked with the right support at the right time no matter where they present. Ask for help and get it first time.

More training for GPs on earlier detection of psychosis (having psychosis, signs and symptoms on their radar) and listening to family and carers. Develop clear clinical pathways for psychosis services that are easy to understand for both professionals and service users

Early intervention means listening to individuals, families, carers/supporters the first time they are expressing concern about delusions, paranoia, odd behavior and psychotic symptoms.

People are left till it is crisis stage and they are being sectioned. In the early stages of a person becoming unwell, with fast access to the right type of support and treatment at home, at the earliest stage, this may prevent an admission.

Listening to family and people who know the person well is crucial. Sometimes people who are experiencing psychosis, delusions, paranoia and hallucinations do not believe or realize that they are unwell. Individuals and families are left trying to cope and to keep their loved ones safe in the most dire situations. Listen, write the referral, organize the assessments, sign post support, get a support plan in place. Don't leave people set adrift.

If individuals have supportive family, a 'whole family approach' is required. Ideally, everyone needs to learn about and understand what they are dealing with as a family. Sometimes the individual might not be able to comprehend what is going on at the time. Family and carers need to understand what is going on medically, and from their loved ones perspective. The individual and family/carers need support to understand the condition by being given accessible resources and compassionate discussion with professionals or others with experience (peer support).

Everyone needs to understand what good care and treatment and rehabilitation should look and feel like. They need to understand their rights and the rights of their loved one. Everyone need to understand that there can be a 'named person'. They need to be aware of advocacy support. They need to be aware of any local and national support groups for psychosis as well as local support organisations in the statutory the Third Sector.

As soon as a person is well enough to comprehend their situation, they must have everything above (including medication) explained to them in a way that they can understand.

People require “not just medication” but “capacity building” to learn about their condition, their triggers, coping strategies and “self-management”. People should be connected to psychosocial interventions such as talking therapies, green prescriptions, self-help groups, third sector services and peer support in order to build creative support and rehabilitation plans.

People must have person centred care/rehabilitation plans in place quickly whether an inpatient or being supported in the community. Where appropriate ‘named persons’ and supportive family should be aware of care plans and rehabilitation goals in place and can provide support and encouragement. Families want to help.”

## Early Intervention in Psychosis engagement project

### ACKNOWLEDGEMENTS

EIP-LERG members in bold type:

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## Early Intervention in Psychosis engagement project

### FOOTNOTE

One point I think is particularly important is of equality and the value of working in partnership. Describing individuals as having lived experience alone, does not recognise or take in to account their professional capabilities, or their power to influence change and reform. Equally describing public sector staff in terms of their professional roles recognises only a part of them. It does not take into account their life experience, their values or their personal motivation for choosing their role. Describing people, in terms of the roles they play, can contribute to the us-vs-them mentality. This sort of opposition can mean that all parties in the room over-estimate the power dynamic that roles carry with them.

This is especially relevant in the context of people who have experienced psychosis, as a number of people I have spoken to have been compelled to receive treatment. The power dynamic that exists in a doctor-patient relationship, does not apply when the context of the meeting is service design, improvement and implementation. Taking a human rights based approach to developing Early Intervention in Psychosis services in Scotland; has to take into account the previously assumed roles of all parties involved. At it's most extreme, this could mean people with lived experience of psychosis working as equal partners, with their own section 22 approved psychiatrist. It may sound unlikely, but it has happened. Care and consideration needs to be given to how this sort of meaningful engagement will work in practice. As it is in everyone's interests to have services that directly address the needs of people who use them.

I tend to think of my experiences as, "symptoms." I tend to view my, "symptoms," through the lens of the medical model. The people I was fortunate enough to meet and talk to, had a broad and rich range of interpretations of their experiences. To counter my own beliefs and assumptions, I've tried as much as possible to let the people we engaged with lead on each part of this report. I hope that I've been able to capture that faithfully.

Hamish Kidd, EIP Engagement Project Worker, Support In Mind Scotland (26<sup>th</sup> February 2021)