Early Intervention in Psychosis Report

March 2021

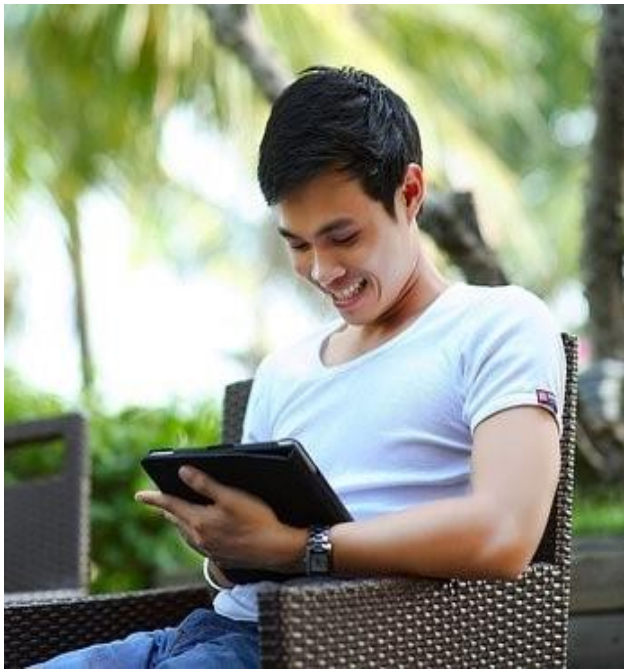
The Scottish Government commissioned Healthcare Improvement Scotland in 2019 to develop a deeper understanding of the Scottish context related to Early Intervention in Psychosis (EIP).

This work sits within the context of Scottish Government policy direction including Mental Health: Scotland Transition and Recovery (2020).

This report has been co-produced with people with lived experience of psychosis, their families and carers.

There is significant variation in the provision of care and treatment for people with first episode psychosis across Scotland, with only one EIP service (Esteem in Greater Glasgow & Clyde), and most care and treatment delivered by community mental health teams (CMHTs).

The evidence is clear, intervening early with the right set of approaches delivered in the right way will lead to significantly improved outcomes for people. The needs assessment highlighted that most services are not consistently delivering all of the core, evidence-based components of EIP.



"Early intervention means avoiding a life lost in the mental health system"

Person with lived experience of psychosis

Scope of work

What Healthcare Improvement Scotland did:

- ✓ Established a national EIP Network, bringing together stakeholders from health, social care, the third sector, and people with lived experience.
- ✓ Conducted a national needs assessment across all 14 NHS boards and linked health and social care partnerships (HSCPs).
- ✓ Undertook a detailed exploration of the current services for people with first episode psychosis in two accelerator sites (NHS Forth Valley and Argyll & Bute HSCP).
- ✓ Considered how relevant quality indicator data can be best collected and optimised in these areas, what is required to improve their services, and what success looks like for local service providers and people with lived experience.
- ✓ Reviewed the relevant SIGN guidelines and promoted their active use across NHS boards and HSCPs.

In this summary report, we outline how EIP can be delivered in urban, semi-urban and rural communities, tailored to local context. We identify workforce and cost implications.

This work was undertaken during the COVID-19 pandemic. The impact of this situation was taken into consideration and is included throughout this report.

> “I know the Scottish Government commissioned this piece of work. They must get the information, whether palatable or not. People with lived experience and carers deserve nothing less.
>
> Person with lived experience of psychosis

What is first episode psychosis?

"People told us that experiencing psychosis for the first time was a life changing event for them and those around them. The full significance of the first episode wasn't always realised at the time.

What do we mean by psychosis?

Psychosis is a medical term which can refer to a single episode or the start of ongoing mental health issues which may lead to the diagnosis of:

- schizophrenia
- schizoaffective disorder
- delusional disorder
- drug induced psychosis
- psychotic depression
- puerperal psychosis
- bipolar disorder with psychotic features

What are the symptoms?

During an episode of psychosis, perceptions, thoughts, behaviours, and mood are significantly altered. People may experience hallucinations (visual or auditory) and delusions (falsely held beliefs). They may have problems with organisation, motivation, self-care and altered emotional experiences. Some people experience an impaired ability to regulate these experiences effectively.

It is often difficult for clinicians to distinguish between symptoms of psychosis and other mental health problems at an early stage.

What is the potential impact?

If undiagnosed, untreated or poorly treated, psychosis can become a long-term condition. A long duration of untreated psychosis is associated with high rates of suicide, more compulsory care, reduced social functioning, greater relapse, high levels of comorbidity, and greater stress on families. Psychosis in early adulthood has the potential to derail social, vocational, and psychological development.

What are the causes?

Psychosis develops due to an interaction between several biological, genetic, psychological, and social factors occurring over a given period.

There is increasing evidence that structural inequalities significantly increase the risk of psychosis, for example enduring racial discrimination or social marginalisation such as homelessness. There is also an association between frequent use of high THC (strong) cannabis and the development of psychotic symptoms.

Who is affected?

First episode psychosis typically occurs in early adulthood, between late teens and mid-thirties.

Since the outset of the COVID-19 pandemic, Esteem in GG&C has recorded a 20 - 25% increase in caseload. This is consistent with anecdotal reporting of an increase in psychosis presentations from all NHS boards.

What does recovery look like?

Traditionally psychosis was viewed as an inevitably deteriorating condition, but we now know that people can recover and go on to live healthy, productive lives. There are three main aspects to recovery:

- Symptomatic recovery – reduction of symptoms, sustained remission, avoidance of relapse and reduction in distress.
- Social recovery – increase in time spent in meaningful employment or training, consistent goals and increase in sense of wellbeing.
- Personal recovery – a fulfilling, meaningful life and a positive sense of identity with self-determination.

Needs assessment learning

All 14 NHS boards provided information, through interviews, about their current service provision. They identified areas of good practice and challenges, highlighting significant variation across Scotland.

Challenges around service provision were raised:

Engagement

- lack of identified systems for involving people with lived experience in service design and delivery
- confidentiality concerns which prevent family involvement
- lack of leadership buy-in
- limited links between primary and secondary care, and
- variable links with other key stakeholders including third sector or social care.

Resources

- general funding challenges for mental health services
- absence of ring-fenced resources for EIP
- potential impact on other mental health services of diverting resources to EIP
- fragmented governance and management structures
- challenges with staff recruitment and retention
- over-reliance on temporary and locum staff
- inadequate access to specialist training and clinical supervision
- high caseloads and lack of capacity, and
- increased need linked to COVID-19.

Service design

- lack of data to understand demand, access, and quality
- long waiting times for psychological therapies
- structural barriers to multidisciplinary team working
- EIP not reflected in strategic plans
- difficult transitions from CAMHS to adult services
- limited access to family therapy
- variation in referral pathways
- absence of dedicated pathways and services
- impact of COVID-19 on quality of care and staff wellbeing, and
- stigma prevents people from seeking help early.

Good practice captured from needs assessment learning

- Shetland's CMHT has a strong focus on team working and linking with other parts of the service. They have daily 20-minute meetings to discuss urgent cases that may have come in overnight. A community mental health nurse attends a GP handover meeting every Friday evening and Monday morning, and the team are involved in weekly virtual ward rounds with adult inpatients.

- In Forth Valley, the multidisciplinary team (medical, nursing, OT, art therapies) and social work are co-located. There is a day unit team, and pre-treatment screening can take place in the same location with a full team on site. A citizen's advice worker comes in once a week. There is a high familiarity and consistency of staff for people. Staff can also support people during additional appointments outwith health as it is in the same building.

- Argyll and Bute use a recovery model to guide their ethos with a focus on working in partnership with people who have lived experience, their families and carers. Their focus is on recovery and empowerment.

- Fife Employability Access Trust have individualised placement support staff who offer a range of interventions including cognitive remediation therapy, employment skills courses, training for employers, and individual placement support services. Working with people who have lived experience, they liaise with employers to identify goals for work, transferrable skills and support people into employment.

Lived experience learning

Engagement with people with lived experience of psychosis has been a central feature of this work. A lived experience reference group was established and the EIP advisory group was co-chaired by a person with lived experience in a paid capacity.

HIS commissioned Support in Mind Scotland to lead engagement events with people with lived experience of psychosis, their families and carers. Over 130 individuals from across Scotland shared their perspectives on what a good early intervention for psychosis would look and feel like:

Engagement

- person-centred care
- recognition and validation of experiences and symptoms
- trusting relationships between family and professionals
- awareness of personal, patient, and workplace rights
- physical safety in inpatient settings that are free from substance use
- negative experiences in healthcare to be acknowledged and addressed
- optimistic outlook with contingencies if setbacks occur
- family's input, observations and concerns noted and actioned, and
- families treated as equal partners in the triangle of care.

Resources

- self-management information, resources and support
- availability of advocacy and support to access, employment support and financial advice
- realistic, accurate information to address stigma and image of psychosis
- information and awareness targeted to teens and young adults
- freedom and time for family members to pursue their own ambitions and lives
- social activities and links to community assets, and
- gatekeepers to have skills to recognise the signs of psychosis.

Service design

- clear, detailed information about medication
- access to peer support
- freedom to make informed choices
- care and treatment that address individual needs and lead to personal benefits, and
- care delivered in a least restrictive way.

Accelerator site learning

NHS Forth Valley and Argyll & Bute HSCP undertook detailed exploration of their existing services for people with first episode psychosis.

First steps for developing EIP in local areas were identified:

Identifying senior leadership and support is an important first step.

Mechanisms should also be established for engagement with key stakeholders, including people with lived experience, third sector, and staff. Engagement sessions and service user and carer questionnaires help build the foundation for agreeing a local vision and measuring performance against standards.

It is important to identify capacity, including existing staff who have training in evidence-based interventions and who have experience working with people with psychosis, for example, psychosocial interventions for psychosis (PSIp), behavioural family therapy (BFT), and cognitive behavioural therapy for psychosis (CBTp).

In addition, it is important to ensure staff have adequate access to clinical supervision.

It is crucial to identify people who are in the early stages of psychosis and understand how people currently access and experience care and treatment. Tools such as stakeholder mapping, force field analysis, and process mapping support this.

There is also a need to collect key data including duration of untreated psychosis, referrals, engagement with services and whether the evidence-based interventions are being delivered, to identify opportunities for improvement.

Current Service Delivery Models of EIP from the Literature

	Specialist Standalone	Hub and Spoke	Augmented CMHT
Description	An integrated, multidisciplinary, specialist team whose sole function is to deliver EIP (assessment, care planning, interventions and key working). Team functions such as training and supervision occur within the team.	A small team at the centre (hub) with other staff with distinct EIP roles placed away from the hub in CMHTs (spoke). The number of spokes and staff time will depend on a range of factors. For example, an area with urban density surrounded by rural areas may require more staff at the hub and fewer in the spokes.	Staff with a special interest or training in the management of psychosis situated within CMHTs with a generic caseload. Clinicians have ring-fenced time for EIP. There are regular meetings to co-ordinate care and treatment with a focus on outreach and work with carers and families, as well as access to psychological therapies.
Population	Suitable for densely populated urban areas of 250,000+. Larger populations would require multiple teams.	Suitable for mixed urban and rural areas or across regions with hubs aligned to inpatient service provision.	There is a lack of evidence in the literature about populations which might be suitable for this model.
Evidence	Evidence consistently shows that compared with standard care, specialist standalone services are an effective and cost-effective method to deliver EIP. There is some evidence of savings within the NHS as well as wider societal savings, including criminal justice, education, employment and housing.	NICE multidisciplinary expert opinion suggests that hub and spoke models may be more likely to provide services meeting EIP principles than augmented CMHTs. The model can be adjusted to suit local and regional requirements. For smaller areas, EIP services may be provided in part by collaborating through regional structures.	There is a lack of evidence about this model in the literature.
Benefits	• less disengagement from mental health services • small reduction in psychiatric hospitalisations • small increase in global functioning • increase in service satisfaction • increased access to family interventions and other psychological services • improved rates of functional recovery • team collaboration which helps support staff wellbeing • long term reduction in suicide risk	• staff can refine and develop specialist skills • staff can concentrate solely on one client group • staff can develop close relationships with other agencies • ability to adjust model to suit local requirements	There is a lack of evidence about the benefits of this model in the literature.
Limitations	• long term benefits are still uncertain • teams may become overstretched if outreaching to remote and rural areas	• limited evidence on effectiveness but perhaps some gain over generic services - for example, reduced hospital admissions compared with usual care and treatment • may not be suitable for more remote or rural areas • risk of staff isolation and limited clinical supervision • lack of specialist therapies • fluctuating case load and risk that staff are diverted to look after more generic caseload	There is a lack of evidence about the limitations of this model in the literature.

Contextual factors influencing choice of service delivery model

Local context will strongly influence selection of the right service delivery model for each area.

- Demographics - a higher number of under 35's, including students, higher levels of deprivation, a higher proportion of migrant, black and minority ethnic people, urbanicity, and a higher prevalence of cannabis use are all likely to increase the incidence of psychosis.
- Geography - rurality, geographical size and the spread of services across an area influence access.
- COVID-19 - increased incidence during the pandemic has impacted on demand for services.
- Workforce - ability to recruit, train, supervise, and retain skilled staff impacts on capacity and capability.
- Existing services - availability, range and location of existing mental health services, including location of inpatient services, and third sector provision influence service delivery.

The geographical context in Scotland means there may be justification for the geographically dispersed areas to identify and test a bespoke service delivery model for EIP.

However, embedding rigorous data collection will be critical to ensuring that any bespoke service delivery model is delivering the evidence-based interventions and approaches that are so vital for improving the outcomes for individuals experiencing psychosis.

> “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.

> The entire NHS mental health system is under-staffed and overstretched, not just wards & specialist services.”

People with lived experience of psychosis

There is strong evidence to support EIP, however there are clear challenges in its implementation.

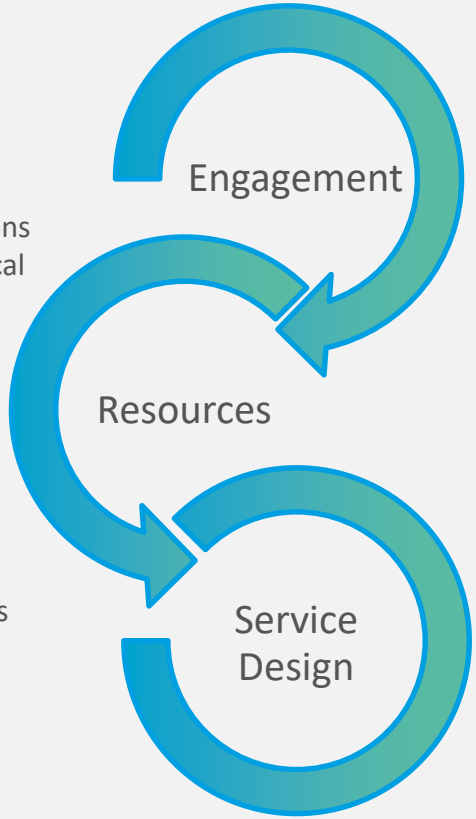
It is important to distinguish between the core components of EIP and service delivery models.

EIP is characterised by core components of **values,** for example, connectedness, hope, identity, meaning and empowerment (CHIME Framework); **interventions,** which are supported by evidence and outlined in SIGN and NICE guidance and the literature; and **service design,** which describes the key characteristics of effective services.

Service model choice will be strongly influenced by both the evidence base and local context and should be co-designed with people with lived experience.

> "[I want] 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.
>
> Person with lived experience of psychosis

Core components of Early Intervention in Psychosis



- biopsychosocial interventions
- CBTp and other psychological interventions
- family interventions
- low dose antipsychotic medication
- regular medication review
- annual physical health reviews
- support for carers
- treatment of co-morbidities
- vocational support
- housing support

- recovery focus
- person-centred
- developmentally and culturally sensitive
- synergistic and collaborative
- hopeful
- empowering
- human rights-based approach
- trauma informed
- family engagement

- quick access to early treatment
- measurement of duration of untreated psychosis
- low caseloads
- embracing diagnostic uncertainty
- integrated multidisciplinary working
- staff with ring-fenced time
- three-year duration
- assertive outreach
- peer support

Service Model Options

- Specialist Standalone
- Hub and Spoke
- Bespoke*

*There is limited evidence for Augmented CMHTs. However a clear need exists to develop a model suitable for smaller boards with geographically dispersed areas. Therefore we are recommending that consideration is given to developing and testing a bespoke model for these areas with rigorous data collection to assess effectiveness.

Identifying need

In Our Vision to Improve Early Intervention in Psychosis in Scotland (June 2019), the Scottish Government estimated national incidence of first episode psychosis at 1,600 cases per year. Due to inconsistencies in data collection, this estimate is based on an expected rate of 29 per 100,000. The true incidence will vary across Scotland dependent on the contextual factors outlined previously.

Anecdotal reports indicate an increase in numbers of people experiencing first episode psychosis due to COVID-19.

Cost of implementing EIP across Scotland

It is not possible to deliver evidence-based interventions and improve long-term outcomes for people with psychosis without investing in ring-fenced staffing.

There is some evidence that providing EIP leads to longer-term cost savings to the NHS and wider society. Best practice suggests that a three-year model is more effective for improving outcomes and reducing pressure on CMHTs. The ***estimated*** cost of EIP care for the standard three years is £10,500 per person per year. This figure is based on the cost of Esteem and specialist EIP services in England.

There are two aspects to the cost of implementing EIP services across Scotland:

1. EIP service staffing provision

2. Set up and development of services:

- equipment
- refurbishment of premises
- national training programme
- public health campaign
- regional/national networks of practice
- improvement support
- digital resources, and
- time for staff in specialist hubs to provide regional support.

The costs below are estimated indicative, for planning purposes and are based on a number of assumptions that will need to be tested in practice.

	EIP service staffing	Set-up, development and support
Year 1	£ 8.4 million*	£2.5 million
Year 2	£16.8 million	£500,000**
Ongoing	£16.8 million	£500,000**

* amount is 50% lower since service not operating at full capacity in first year

** from year two onwards for national training programme, public health campaign, improvement support, learning system, networks and regional support

> People who experienced delays in initial access to services, told us that they were more likely to have to contact out of hours, crisis or emergency services.

Recommendations

1. All NHS boards should establish early intervention in psychosis services which enable reliable delivery of the evidence-based interventions and minimise the duration of untreated psychosis.

Engagement

2. NHS boards, local authorities, IJBs, HSCPs and third sector should collaborate to develop and implement a shared vision for ensuring effective responses for individuals experiencing psychosis. This should include:
   - establishing local multi-professional groups to lead the work
   - reflecting the vision in local strategies and plans, including regional delivery plans, and
   - working across boundaries of primary and secondary, children and adults, and statutory and voluntary.
3. EIP services should be developed and implemented with a focus on engagement and co-design with experts, including people with lived experience. This needs to include:
   - developing local lived experience reference groups
   - maintaining the national EIP lived experience reference group and advisory group, and
   - identifying local clinical leadership.
4. HIS should facilitate a national learning system for EIP, including:
   - offering opportunities to network and share innovative practice whilst boosting the resilience and skills of staff and other stakeholders to lead change, and
   - establishing regional networks in the north, east and west of Scotland in line with existing regional planning arrangements.

Resources

5. There is a need to identify additional recurring, ring-fenced funding for EIP.
6. The Scottish Government and NHS Education for Scotland should support the establishment and delivery of a workforce development programme which ensures that there are enough appropriately trained staff to support service development:
   - develop a knowledge and skills framework for EIP
   - develop Essentials of EIP training for all staff to introduce values, knowledge, and skills needed to deliver EIP
   - increase availability of training and supervision for staff delivering EIP, for example BFT, CBTp, PSIp, MAP health behaviour change, and
   - deliver training for wider stakeholders, for example, police and education staff, who encounter people with first episode psychosis.

Service design

7. HIS should support the routine evaluation of the effectiveness of services by:
   - developing and testing quality indicators, and
   - rolling out agreed quality indicators nationally, in partnership with Public Health Scotland.
8. HIS should identify and support pathfinder sites to test hub and spoke and bespoke service models in order to understand how they may be used to deliver quality EIP services in Scotland.
9. Local health improvement teams should develop and implement awareness campaigns to provide information on the early signs of psychosis, and where possible a national approach should be taken.

> 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 person-centred planning focusing on the patient's goals.
>
> **Person with lived experience of psychosis**

Next steps

Key short-term actions which will support the development of EIP in Scotland:

- develop and test quality indicators
- establish and deliver a workforce development programme including training for pathfinder sites
- maintain a focus on engagement with people with lived experience
- deliver the national learning system, and
- identify pathfinder sites and test delivery models.

Acknowledgements

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We are thankful to the members of the EIP lived experience reference group and people all over Scotland with lived experience of psychosis, their families and carers who gave their time freely and shared their personal experiences to help us better understand the needs of people with lived experience of psychosis.

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Finally, we would like to thank NHS Greater Glasgow and Clyde for facilitating the secondment of Dr Suzy Clark to provide clinical advice to this work.

> Stigma still exists around diagnosis and individuals can get distracted and caught up in a diagnosis, or downright terrified. Use it sparingly and wisely. Focus on alleviating the distress and understanding what that person needs to feel safe, to heal and to thrive. Ask people what they need. Listen more.
>
> **Person with lived experience of psychosis**

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