British Journal of General Practice

Collaboration across the primary/specialist interface in early intervention in psychosis services: a qualitative study

Rickett, Michelle; Kingstone, Tom; Gupta, Veenu; Shiers, David; French, Paul; Lennox, Belinda; Crawford, Mike; Penington, Edward; Hedges, Anna; Ward, Jo; Williams, Ryan; Bateman, Paul; Chew-Graham, Carolyn

DOI: https://doi.org/10.3399/BJGP.2023.0558

To access the most recent version of this article, please click the DOI URL in the line above.

Received 24 October 2023 Revised 13 February 2024 Accepted 11 March 2024

© 2024 The Author(s). This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 License (http://creativecommons.org/licenses/by/4.0/). Published by British Journal of General Practice. For editorial process and policies, see: https://bjgp.org/authors/bjgp-editorial-process-and-policies

When citing this article please include the DOI provided above.

Title:

Collaboration across the primary/specialist interface in early intervention in psychosis services: a qualitative study

Authors:

Michelle Rickett; Tom Kingstone; Veenu Gupta; David Shiers; Paul French; Belinda Lennox; Mike Crawford; Ed Penington; Anna Hedges; Jo Ward; Ryan Williams; Paul Bateman; and Carolyn A. Chew-Graham

Dr Michelle Rickett, corresponding author, Research Associate, School of Medicine, Keele University, Keele, UK, ORCID 0009-0001-2503-9951

Dr Tom Kingstone, Senior Lecturer, Mental Health and Wellbeing, School of Medicine, Keele University, Keele, UK, ORCID 0000-0001-9179-2303

Dr Veenu Gupta; Assistant Professor, Lived Experience Research, Department of Psychology, University of Durham, UK; Research Associate, Department of Nursing and Public Health, Manchester Metropolitan University, UK, ORCID 0000-0001-5082-5068

Dr David Shiers; Carer; Honorary Research Fellow, School of Medicine, Keele University, Keele, UK, ORCID 0000-0003-2531-5837

Dr Paul French; Reader in Mental Health, Department of Nursing and Public Health, Manchester Metropolitan University, UK, ORCID 0000-0003-4300-387X

Prof Belinda Lennox; Professor, Psychiatry, Department of Psychiatry, University of Oxford, UK, ORCID 0000-0002-4972-8786

Prof Mike Crawford; Professor, Mental Health Research, Division of Psychiatry, Imperial College London, UK, ORCID 0000-0003-3137-5772

Mr Ed Penington; DPhil candidate, Researcher in Health Economics, Department of Psychiatry, University of Oxford, UK, ORCID 0000-0001-7668-438X

Dr Anna Hedges; Child and Adolescent Psychiatrist, Greater Manchester Mental Health NHS Foundation Trust, UK

Ms Jo Ward; Carer; Advanced Clinical Practitioner, Cheshire and Wirral Partnership NHS Foundation Trust, UK & DHU Healthcare, UK

Dr Ryan Williams; PhD student, Division of Psychiatry, Imperial College London, UK, ORCID 0000-0001-8486-4903

Dr Paul A. Bateman; Statistical Programmer, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK, ORCID 0000-0003-0626-7809

Prof Carolyn A. Chew-Graham, Professor of General Practice, School of Medicine, Keele University, Keele, UK, ORCID 0000-0002-9722-9981

Collaboration across the primary/specialist interface in early intervention in psychosis services: a qualitative study

<u>Abstract</u>

Background

People with new psychotic symptoms may be managed within an Early Intervention in Psychosis service (EIP). They may be discharged back to primary care at the end of their time in an EIP service.

Aim

To explore the role of primary care in supporting people with psychosis in an EIP service.

Design and Setting

Qualitative study, within a programme of work to explore the optimum duration of management within an EIP service.

Methods

Semi-structured interviews with people in EIP services, carers, general practitioners (GPs) and EIP practitioners.

Results

GPs report difficulties in referring people into EIP services, have little contact with people who are supported by EIP services and are not included in planning discharge from EIP service to primary care.

Conclusions

This study suggests that GPs should have a role in the support of people within EIP services (in particular monitoring and managing physical health) and their carers. Inclusion of GPs in managing discharge from EIP services is vital. We suggest that a joint consultation with the service user, their carer (if they wish) along with EIP care co-ordinator and GP would make this transition smoother.

Keywords

Severe mental illness, Early Intervention in Psychosis, qualitative methods, primary care

How this fits in

Early Intervention in Psychosis (EIP) service users may be referred from, and discharged back to, primary care. There is limited research on patient and carer experience of discharge to primary care from EIP services and little guidance around planning and implementation of discharge. This paper explores experiences of EIP care and discharge from the perspectives of service users, carers and healthcare professionals in EIP services and primary care. It explores the patient journey through EIP services, highlights the lost connection with

primary care, and makes recommendations for more collaboration between primary and specialist care, particularly around physical health monitoring and management, which might improve patient experience and outcome.

Collaboration across the primary/specialist interface in early intervention in psychosis services: a qualitative study

Introduction

People who develop new psychotic symptoms may present to primary care and be referred to, and accepted into, Early Intervention in Psychosis (EIP) services. These are multidisciplinary, community-based mental health teams offering treatment to people who experience a first episode of psychosis. EIP services are designed to intervene to reduce the duration of untreated psychosis, which has been associated with a worse prognosis. EIP service input has been shown to reduce negative outcomes such as coercive crisis management and hospitalisation under the Mental Health Act. All service users (SUs) should have a dedicated EIP care co-ordinator. Many are also supported by informal caregivers, typically close relatives including parents, children, partners and siblings, who can experience lack of support and negative impacts on their own health and wellbeing.

In the United Kingdom, EIP services are time-limited, offering up to three years of treatment. SUs are then discharged either to a community mental health team (CMHT), which offer less intensive contact and interventions, or directly to primary care. Factors influencing discharge to a CMHT include enduring psychoses, referral to EIP from inpatient services, and longer time under EIP care.⁴ There is little guidance around planning and implementation of discharge from EIP to other services⁵ and particularly to primary care,⁶ even though the majority of people are discharged to primary care.⁷ Previous studies of transition from EIP services have suggested that better inter-agency collaboration and SU preparation for discharge, particularly the transition to primary care, is needed.⁸ The need for primary care to ensure physical needs are met, even when SUs are actively engaged with EIP services, has been emphasised previously.⁹

People with psychosis are at risk of developing physical health problems such as diabetes and cardiovascular disease with the risk of early death. ^{10, 11} Physical health monitoring should be carried out at the start of treatment and at least annually, and this may happen in primary care or the EIP service. ¹² Some people may not have appropriate monitoring and management whilst others may have duplicate assessments. ¹³

The aim of this qualitative study was to understand and contextualise the experiences of EIP and the role of primary care in supporting service users, from the perspectives of recipients and providers of care.

Methods

This qualitative study was part of a larger NIHR-funded mixed methods programme – EXTEND, which aims to examine the impact of duration of EIP care on patient outcomes.

Our qualitative methods were underpinned by interpretivism to support exploration of contexts, meanings and interactions in relation to EIP services from multiple stakeholder

perspectives. Semi-structured interviews were used to explore views and experiences of EIP service users, carers, healthcare professionals from primary and specialist care, managers, and commissioners about EIP services.

Patient and public involvement (PPI) was integral to the study. Our two PPI co-investigators (VG, DS) and patient and carer advisory group (EXTENDing group) co-designed topic guides, public-facing documents and recruitment strategies. They also contributed to the interpretation of data during analysis meetings with the research team and via email feedback.

Recruitment of Participants

We recruited EIP SUs and carers at the time of, or shortly after discharge from an EIP services (we excluded SUs lacking capacity or expressing suicidal ideation), general practitioners (GPs), EIP practitioners, and managers and commissioners of mental health services.

SUs and carers were recruited using both purposive and convenience sampling. Potential participants were identified through Mental Health Trusts (MHTs) across England and who reported a mix of high and low duration of treatment. Other participants self-identified by responding to a study flyer shared via social media (X^R), mental health networks, support groups and charities. The flyer included a QR code linking to the EXTEND website.

EIP practitioners and managers were identified through participating MHTs. GPs were identified through professional networks and snowballing; we targeted diversity in relation to locality, size and type of practice.

An information sheet and 'consent to contact' form were used. On return of a 'consent to contact' form, individuals were contacted by the study researcher (by email or telephone), who checked their eligibility against inclusion criteria, and invited to participate in an online (Microsoft Teams^R) or telephone interview, depending on participant preference. MR conducted screening calls before interviews with SUs and carers to assess capacity and to check eligibility (inc. age, care under EIP service, time of discharge). SUs were given the option to be interviewed with a carer.

Consent forms were completed electronically before or at the start of the interview. At the end of the interview, participants were asked if they wished to receive a plain English summary of the research findings and/or related publications. SUs and carers were offered a shopping voucher to recompense them for their time and GPs were reimbursed as per BMA guidance.

Data generation

Semi-structured interviews were conducted by MR, a female post-doctoral researcher with qualitative research expertise. Interview participants were not given any information about the researcher other than being employed by Keele University.

A topic guide supported exploration of experiences and views of EIP services; duration of care; decision-making about discharge; and arrangements for ongoing care. Topic guides were developed with co-investigators and people with lived experience as EIP service users or carers (VG, DS, EXTEND-ing group members). The guides were modified iteratively alongside data generation and analysis. ^{16,17} Data collection continued until information power was achieved. Information power is an alternative concept to saturation in qualitative research and involves pragmatic judgements based on aims, specificity, theory, dialogue and analysis. ¹⁴ Interviews were conducted between September 2022 and September 2023.

The interviews were audio-recorded, transcribed by a professional transcribing company, then checked and anonymised by the first author (MR), who also compiled field notes after each interview. Analysis was performed using qualitative research software (NVivo 11). Transcripts were not returned to participants for comment and participants were not asked to give feedback on the findings. Data were thematically analysed using principles of constant comparison; this involved the researcher reading and re-reading transcripts, identifying and organising codes, and constructing themes. ^{15,18} A framework approach was used to draw analyse from different participant groups together; ¹⁹ the framework focused on the SU journey through EIP services and the complexities around discharge. MR led analysis and met regularly with research team members (CCG, TK, VG, DS), with a range of backgrounds and disciplines, to check data interpretation and agree themes. The EXTENDing group also provided feedback on themes.

Results

Fifty-five interviews were conducted: 13 EIP SUs, 10 carers, 8 GPs (salaried or partners), 23 EIP practitioners, managers and 2 commissioners. One interview was dyadic (joint interview with SU and carer). All EIP practitioners and managers were recruited through MHTs. Eleven SUs were recruited through MHTs and two through SU groups. Two carers were recruited through a MHT and eight through social media and online networks. Commissioners and GPs were recruited through professional networks. Twenty-six people replied to our social media SU and carer recruitment flyer but either did not reply to follow up contacts, or, following a screening call (conducted by MR), were found to be ineligible as they had not been under EIP care, or were thought to be "imposter participants" claiming to be EIP SUs or carers but unable to answer questions about EIP care. Interviews lasted between 25 minutes and 50 minutes.

Key participant characteristics are presented in Tables 1-4.

Table 1 here

Most SUs disclosed physical and/or mental health conditions in addition to the diagnosis of psychosis.

Table 2 here

A minority of carers (n=3) reported physical and/or mental health diagnoses. Five carers lived with the person they provided care for.

Table 3 here

Table 4 here

Our findings are presented under four themes; barriers to accessing EIP services; perceived value of EIP services; lost connection with primary care and discharge planning. Illustrative data are presented to support the analysis along with identifiers (e.g., HCP17).

Barriers to accessing EIP services

EIP practitioners felt the initial referral process was straightforward:

So, anyone pretty much can refer directly into EIP, so GPs can come directly even though we have what's called a Single Point of Access within the Trust, so all GPs usually refer into that SPA service we call it...So if there's a family member worried about their loved one ...and people themselves can refer. ...so pretty much open-door referral policy yes. (HCP16)

GPs described limited knowledge of the criteria for admission to EIP care. Many GPs expressed frustration, a sense of powerlessness at rejected referrals and concern for patient safety and wellbeing:

I referred her to the early intervention, and they did an assessment and basically felt that she wasn't ill enough to be under their care and just to refer her to the community mental health team because these were just symptoms of anxiety and depression and stress, which I felt was not the route that I would've suggested...So it was quite upsetting... I felt really disappointed for this lady because it was a big thing for her to disclose it to me.... I was saying, 'Well there's this service called Early Intervention and I think this would be really good', almost trying to win her around because she was embarrassed to talk about it and then had to come back and be like, 'Yeah and the referral was rejected', which obviously doesn't fill her with confidence. (GP1)

Perceived value of EIP services

EIP staff described the breadth of care offered, and the holistic approach taken, with an emphasis on patient-centred engagement and relationship-building being key to the success of the EIP model:

We have the ability to concentrate on engagement and...proper patient-centred care, it's not just a throwaway line, and we have access to vocational support, to psychology, to social recovery support. (HCP15)

SUs talked about being supported and understood by their care coordinator:

(name of care coordinator) knew so much about me as well, so after three years I didn't have to tell her who somebody was or anything because she just knew and you'd be like how's this person, how's that person, she knew everything about me, so I had no worries there. (SU2)

EIP care coordinators were recognised as essential to the success of EIP relationshipbuilding:

The relationship and the attachment they have to us is that kind of key bedrock of what helps people. (HCP17)

SUs described how the EIP service had given them better understanding of their condition, which helped them feel less isolated and more in control:

It's talking to people, people who have really good expertise in psychosis. Because I had no idea what it was. I had all these awesome people around us, like the CPN (Community Psychiatric Nurse) and the support worker. I didn't feel alone, like I could go to them. (SU6)

GPs had limited awareness of the duration of EIP care, what EIP care involves, and the discharge process:

I saw a lady the other day and she was actually discharged from them because she'd been under them for three years, which apparently is the maximum amount of time that they can be under them, which I wasn't aware of. (GP1)

Some GPs were also unsure about the respective roles of EIP and crisis teams:

I think we'd send them to the crisis team. I mean I never heard the term EI until recently. (GP6)

Therefore, while supportive relationships were reported to be established between SUs and EIP practitioners during the period of EIP care, GPs reported little awareness of the function of EIP services.

Lost connection with primary care

SUs appreciated the strong supportive relationships they had established with EIP practitioners but reported little to no contact with their GP. As a consequence, SUs preferred to speak with EIP practitioners about physical and mental health:

The GP practice don't know an awful lot really, I think it's good that the hospital (EIP service) keeps you there quite a few years, I think it's nice really, you don't have to deal with your normal GP. Because like I said I don't actually know who my GP is... (SU2)

GPs suggested their role was to refer patients into EIP services (directly or through a crisis team); they would then have little involvement while patients were under EIP care. GPs reported little engagement with EIP care coordinators during the period of EIP care or planning for discharge:

I think the experiences I have had, have given me a reasonable level of trust that those initial stages are handled pretty well in a way that I don't have to be overly involved as a GP you know, beyond the referral stage. (GP3)

Physical health checks and monitoring for SUs were reported to be undertaken by EIP teams:

So, we're the people meant to be responsible for that. So, the cardiometabolic risk factors, so bloods and BMI and blood pressure and smoking etc., and particularly regarding the prescribing of antipsychotics. So, we're responsible for monitoring that. We don't ask the GPs to do it. (HCP10)

GPs were perceived by EIP practitioners and carers to have responsibility for physical health checks, only when EIP services lacked capacity:

...unfortunately, we don't have a physical health team attached to us at the moment. So, it would be sharing that with the GP and what have you. (HCP22)

I think for that they referred him to his GP because I think they were overloaded with people wanting physical help...... and he has been using the same GP for many, many years, so sent him in for the GP and then the GP just conducted physical health evaluations. (CAR3)

One GP, working in a small practice, reported that they continued to conduct physical health checks with EIP service users, as a way of 'touching base' and maintaining a relationship:

We still try and contact the patient and we would still try and have a review in-house. That review might be that we say, 'Look, we'd like to see you... would you mind coming in just to meet us so we can just touch base with you, see how you're doing and whether there's anything else we need to help you with?' (GP8)

In addition, one SU did have an established relationship with the GP, which continued whilst he was under EIP care.

Discharge planning

EIP practitioners and managers reported that discharge from EIP was planned well in advance. This was due to a recovery-centred approach and long waiting lists for CMHTs:

So, we start thinking about it sometimes six or 12 months ahead and we have a chat about what a person's needs might be. (HCP10)

I think we work towards discharge from very early on. Although it's a three-year pathway, we are working ... this is our ideal, so we're working towards discharge. I don't think we get to the end of the three years and go, 'Oh, we need to do some discharge planning. (HCP14)

For discharge to CMHT, it was reported that handover meetings were held, involving the EIP care coordinator, new CMHT care coordinator and SU. EIP professionals were aware that this transition could be difficult and required a personalised approach:

So, we would generally try and organise a couple of meetings joint with the case manager from the other team. So yeah, just sit there and talk, talk about what we've done, what the person wants to do and just so they feel comfortable with their new case manager before we fully discharge them. And we can stretch that out a bit as well if we think someone is particularly anxious about the transition. (HCP13)

Discharge planning to primary care was seen by EIP practitioners as more straightforward with little contact needed, other than via a discharge letter:

I think the liaison is maybe a little less comprehensive than with the adult mental health teams, just because of the nature of the sort of care that's expected afterwards. So, we would send the GP a letter, to update the GP about the person. There wouldn't necessarily be a meeting or a discussion; it would be information sharing by letter, really. (HCP11)

If we don't feel that they need to be in secondary care, we'll just sort of like discharge them back to their GP...... obviously we can just write to the GP and discharge the care back and the consultant will send their letter straight to the GP as well. (HCP7)

EIP practitioners felt current communication with GPs was sufficient:

We send a letter usually, but if the GP needed to be involved (in meetings) we'd invite the GP. It's very rare GPs come, we do invite them to meetings and professional meetings sometimes talking about somebody's care, but yeah it would be a letter. And the GP could always contact us (HCP16)

GPs, however, expressed concerns about EIP discharge communication being limited to letters which could be received some time after discharge:

Well, there have been instances where I haven't been aware the person has been discharged. And I can't remember ever being in a situation where somebody's

deliberately made a point to phone me to say, your patient's being discharged. And often there's a delay in paperwork so that's my impression of it. So, I don't think there is a clear communication to the GP at point of discharge. (GP5)

Detailed discharge letters can be an important therapeutic tool for SUs and provide a shared narrative of their journey through EIP. GPs, however, reported them to be an unwieldy form of communication:

The mental health discharge letters they can be seven, eight, ten pages long telling us great depth about the full mental state, exam that they've done and things like that. And then just very hard within there to see what the kind of salient points of the case are. You know, the detail is there, but I'm run off my feet in the clinic and I've been given this one sort of eight-page letter of someone who's been in the services a while and they've now felt is fit to be discharged. (GP2)

GPs suggested that SUs discharged to primary care could still have substantial ongoing support needs. They expressed concern about managing complex antipsychotic medication without specialist support:

The main challenges that I have had have been when the mental health services have wanted to discharge people on like say new anti-psychotic medications, either medication or depot, but you know, really that should be all under kind of formal shared care agreements between secondary care and primary care and there's an increasing push for people to be discharged from the team I think and GPs to take full ownership of the anti-psychotic medications. (GP3)

One GP suggested a transitional approach to discharge could improve communication and joint-working between primary/EIP care, but acknowledged this would require additional time:

Maybe (SUs could) stay under the early intervention team for longer, but more on an arm's distance. And so, as GPs, we could kind of see them regularly, but then if we felt we had concerns we could liaise with the early intervention and try and help manage them more remotely, but with their experience, their guidance....I think there would definitely be scope for us to work more with the early intervention team, but it's just finding the time really. (GP1)

SUs and carers expressed worry and uncertainty about discharge from EIP:

I guess I am a bit afraid about what comes next because it does kind of feel like somebody has took the lead off, kind of thing. You won't be able to talk to the people like you've formed a connection with for three years and that's kind of scary. But you know, I feel like I have the tools to deal with it than I did three years ago. (SU6)

Personally, I'm terrified (of discharge) because all my help I know where to go, I know where to get the help immediately if I need it. Any problems I know what to do and I know his care coordinator so well that I feel comfortable. (CAR7)

One SU described how she had relapsed after discharge to primary care, and felt that her concerns about discharge had contributed to this:

I was really sad to be honest, it's like a weird feeling it's been so long just having someone there as like a bit of a comfort blanket and then all of a sudden they're not going to be there anymore and you just think, oh no. Because anything I needed I could call her or text her whenever I wanted. So obviously not having that there was pretty worrying. (SU2)

Most SUs described concern about not having continuity with one GP, having to re-tell their story following discharge:

What I have asked is although I've got a named GP at my doctors, it has changed where it can be multiple people that you've not really seen before. So, I did ask my consultant yesterday if I could... I think for me, it's about someone who just has a little bit of an idea about what's gone on previously.....but it's a bit annoying, I think, especially when you are not feeling good mentally, when you're having to repeat yourself and tell your story time and time again. (SU1)

Carers also felt disconnected from primary care, expressing fear they would not be able to access support for their loved ones after discharge:

My first port of call would be the GP. I wouldn't know who I would be speaking to there...and I would feel like we have to go back to square one again and start again. And so I would be doing that out of desperation with no confidence that there would be an appropriate reaction. (CAR8)

Though complex medication regimes were of concern to GPs, medication management could offer a mechanism for SUs to build relationships with their GP:

One thing that was really helpful and has now stopped is she was having her Depot at the GP and she was absolutely happy to go. She felt comfortable with the (practice) nurses, and they had a chat. It wasn't the same one I don't think, and she'd say, "Oh, it was (name) today and we talked about this." So that did build a certain relationship with the practice. (CAR4)

Discussion

Summary

This qualitative study illustrates the tensions across the primary/specialist care interface for EIP services., GPs and SUs reported difficulties in accessing EIP services and challenges at the point of discharge. As referrals to EIP services are often made at crisis point, SUs may not have been known to their GP before referral, and there may not be a pre-existing relationship to pick up on discharge from the service. We report that SUs under an EIP

service may have little contact with a GP Further, physical health monitoring may not be done in primary care.

Experiences whilst in EIP services were described by most SUs and carers as positive, with SUs highlighting the benefits of regular and continuing support from care coordinators. Discharge to CMHT was reported to be well-planned and proactive, although sometimes impeded by long waiting times for admission to CMHT. This contrasted with discharge to primary care being seen by EIP professionals as needing no more than a letter to the GP informing them of the discharge. Both SUs and carers described feelings of abandonment when discharged to general practice, often to a GP they did not know.

Strengths and Limitations

This study explores experiences of EIP services from multiple perspectives and illustrates the complexity of the patient journey through these services. We recruited a diverse sample and analysis was conducted by a multidisciplinary team.

There are limitations to this study. Of the thirteen SU participants, only four were male yet most people in EIP services are male. Seven of the ten carer participants were caring for male SUs, which gave additional insight. Four SUs were non-White despite attempts to recruit an ethnically diverse sample through MHTs and social media. SU participants were all stable in terms of their mental health at the point of interview. Carers shared experiences of SUs who were unwell, to support a broader understanding. Most SU participants had become unwell prior to the COVID-19 pandemic; more recent experiences of a new psychotic illness may reveal important differences. We gave SUs and carers the opportunity to be interviewed together if they preferred: only one dyadic interview was completed.

Comparison with existing literature

Our study adds to the very limited research on patient and carer experience of discharge to primary care from EIP services, even though this is the most common outcome following EIP service input.^{21,22} SUs value the continuity of care provided by EIP services – particularly the opportunity to build a therapeutic relationship with a named care coordinator - which is consistent with previous literature.²³ Studies have shown that continuity of care in EIP services results in higher SU satisfaction and better health outcomes.²⁴ Similarly, continuity for people with severe mental illness leads to better health outcomes, reduced hospital admission, and is more cost-effective.²⁵

Supporting the physical health needs of people with SMI is one of the 5 clinical priorities of the CORE20PLUS5 approach²⁶ and is particularly urgent given the 15-year mortality gap between people with SMI and the general population. The Lester update emphasised the importance of physical health monitoring from the earliest stages of a psychotic illness, particularly when antipsychotic medication is prescribed²⁷ as the risk of weight gain in the first 12 months requires early intervention.²⁸

The lack of contact with primary care, whilst people are managed by EIP services, reduces opportunities for SU and carers to establish relationships with general practice and engagement with physical health monitoring.²⁹

Implications for research and practice

We suggest it would be beneficial for closer connections to be maintained between people within EIP services and their registered general practice – there are various ways to achieve this. This could be a 'named GP' to take over prescribing on discharge and/or a Health Care Assistant or Practice Nurse tasked with conducting the physical health check.³⁰ Mental health professionals, embedded within primary care teams (ARRS³¹), could maintain contact with SUs under EIP care and liaise with care co-ordinators, GP and carer to plan discharge. A joint consultation between the SU, their carer (if they wish), care co-ordinators and primary care clinician would support effective transitions. Supporting the SU and carer to understand when and how to access primary care would be valuable, particularly if the person were to become unwell again. Closer connections with primary care would also promote relationship-based care, which is already a hallmark of the care that people receive within EIP services. Our findings could be used to support the education and training of primary and specialist care practitioners, and commissioners.

We suggest that current discharge letters are not used effectively to communicate with primary care. A standard structured discharge letter should be jointly developed which summarises the key points of importance for primary care clinicians.³²

Primary care also has a role in supporting carers,³³ so maintaining contact with, and offering support to, the carer of a person being managed by EIP services is vital.

Funding

This study/project is funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Ref: NIHR203277). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

EXTEND study: https://www.psych.ox.ac.uk/research/extend
CC-G part-funded by West Midlands Applied Research Collaboration

Ethical Approval

Research ethics approval was obtained in September 2022 from the REC (22/NS/0113) and HRA (IRAS 313927)

Provenance

Freely submitted, externally peer-reviewed

Acknowledgements

We would like to thank all interview participants for their time. Thank you to members of the EXTENDing group (https://www.psych.ox.ac.uk/research/extend/extend-ing) for their contribution to the EXTEND qualitative study, particularly their input to data analysis. CCG is part-funded by West Midlands ARC.

Competing interests

The authors have declared no competing interests

References

- 1. Marshall M, Lewis S, Lockwood A et al. Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. *Arch Gen Psychiatry*. 2005. 62(9):975–83.
- 2. Correll CU, Galling B, Pawar A et al. Comparison of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis: A Systematic Review, Meta-analysis, and Meta-regression. *JAMA Psychiatry*. 2018. Jun 1;75(6):555-565.
- 3. Onwumere J, Shiers D, Chew-Graham CA. The needs of carers of people with psychosis in primary care. *Br J Gen Prac*. 2016. 66(649): 400-401. DOI: 10.3399/bjgp16X686209
- 4. Ahmed S, Peters KZ, Chakraborty N. Discharges from an early intervention in psychosis service: The effect of patient characteristics on discharge destination. *Early Interv Psychiatry*. 2019. 13(4):740-744. doi: 10.1111/eip.12552. Epub 2018 Mar 7. PMID: 29512312.
- 5. Loughlin M, Berry K, Brooks J, Bucci S. Moving on from early intervention for psychosis services: Service user perspectives on the facilitators and barriers of transition. *Early Interv Psychiatry*. 2019. 13(6):1396-403.
- 6. Lester H, Khan N, Jones P et al. Service users' views of moving on from early intervention services for psychosis: a longitudinal qualitative study in primary care. *Br J Gen Prac*. 2012. 62(596), 183–190. https://doi.org/10.3399/bjgp12X630070
- 7. Puntis S, Pappa S, Lennox B. What happens after early intervention? Mapping early intervention in psychosis care pathways in the 12 months after discharge. *Early Interv Psychiatry*. 2024. 18:(1): 49-57 https://doi.org/10.1111/eip.13433
- Woodward S, Bucci S, Edge D, Berry K. Barriers and facilitators to "moving on" from early intervention in psychosis services. *Early Interv Psychiatry*. 2019. 13: 914– 921. https://doi.org/10.1111/eip.12708
- 9. Lester H, Khan N, Jones P et al. Service users' views of moving on from early intervention services for psychosis: a longitudinal qualitative study in primary care. *Br J Gen Prac*. 2012. 62(596), 183–190. https://doi.org/10.3399/bjgp12X630070

- 10. Álvarez-Jiménez M, González-Blanch C, Crespo-Facorro B et al. Antipsychotic-Induced Weight Gain in Chronic and First-Episode Psychotic Disorders. *CNS Drugs*. 2008. 22, 547–562. https://doi.org/10.2165/00023210-200822070-00002
- 11. Nielsen RE, Uggerby AS, Jensen SO, McGrath JJ. Increasing mortality gap for patients diagnosed with schizophrenia over the last three decades--a Danish nationwide study from 1980 to 2010. *Schizophr Res.* 2013. 146(1-3):22-7. doi: 10.1016/j.schres.2013.02.025. Epub 2013 Mar 21. PMID: 23523021.
- 12. Perry BI, Holt RIG, Chew-Graham CA et al. 2023 update (with acknowledgement to the late Helen Lester for her contribution to the original 2012 version) Positive Cardiometabolic Health Resource: an intervention framework for people experiencing psychosis and schizophrenia. Royal College of Psychiatrists, London. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/ncap-library/eip-2024/ncap-lester-tool-intervention-framework.pdf?sfvrsn=21e45dbd_15 (accessed 23.1.24)
- 13. Firth J, Siddiqi N, Koyanagi A et al. The Lancet Psychiatry Commission: a blueprint for protecting physical health in people with mental illness. *Lancet Psychiatry*. 2019. 6(8), 675-712, https://doi.org/10.1016/S2215-0366(19)30132-4.
- 14. Malterud K, Siersma V. D, Guassora A. D. Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*. 2016. *26*(13), 1753-1760.
- 15. Nowell I, S., Norris J, M., White D, E., Moules N, J. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Methods*. 2017. 16(1) https://doi.org/10.1177/1609406917733847
- 16. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006. 3, 77–101. https://doi:10.1191/ 1478088706qp063oa
- 17. Creswell J. 2007. Data analysis and representation. In J. Creswell (Ed.), Qualitative inquiry and research design: Choosing among five approaches (2nd ed., pp. 179–212). Thousand Oaks, CA: Sage.
- 18. Nowell I.S, Norris J.M, White D.E, Moules N.J. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Methods*. 2017. 16(1). https://doi.org/10.1177/1609406917733847
- 19. Gale NK, Heath G, Cameron E et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013. 13(1), 1-8.

- 20. Ridge D, Bullock L, Causer H et al. 'Imposter participants' in online qualitative research, a new and increasing threat to data integrity? *Health Expect*. 2023. 26(3):941-944. doi: 10.1111/hex.13724.
- 21. Puntis S, Pappa S, Lennox B. What happens after early intervention? Mapping early intervention in psychosis care pathways in the 12 months after discharge. *Early Interv Psychiatry*. 2024. 18:(1): 49-57 https://doi.org/10.1111/eip.13433
- 22. Lester H, Khan N, Jones P et al. Service users' views of moving on from early intervention services for psychosis: a longitudinal qualitative study in primary care. *Br J Gen Prac.* 2012. 62(596), 183–190. https://doi.org/10.3399/bjgp12X630070
- 23. Lester H, Birchwood M, Bryan S et al. Development and implementation of early intervention services for young people with psychosis: case study. *Br J Psychiatry*. 2009. 194(5):446-50. doi: 10.1192/bjp.bp.108.053587. PMID: 19407276.
- 24. Loughlin M, Berry K, Brooks J, Bucci S. Moving on from early intervention for psychosis services: Service user perspectives on the facilitators and barriers of transition. *Early Interv Psychiatry*. 2019. 13(6):1396-403.
- 25. Adair C, McDougall M, Mitton C et al. Continuity of Care and Health Outcomes Among Persons With Severe Mental Illness. *Psychiatr Serv.* 2005. 56 (9): 1061-1069. https://doi.org/10.1176/appi.ps.56.9.1061
- 26. GOV.UK. Severe mental illness (SMI) and physical health inequalities: briefing. Public Health England. 2018. www.gov.uk/government/publications/severe-mental-illness-smi-physical-health-inequalities/severe-mental-illness-and-physical-health-inequalities-briefing (accessed 12.12.23).
- 27. Perry BI, Holt RIG, Chew-Graham CA et al. 2023 update (with acknowledgement to the late Helen Lester for her contribution to the original 2012 version) Positive Cardiometabolic Health Resource: an intervention framework for people experiencing psychosis and schizophrenia. Royal College of Psychiatrists, London. <a href="https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/ncap-library/eip-2024/ncap-lester-tool-intervention-framework.pdf?sfvrsn=21e45dbd 15 (accessed 23.1.24)
- 28. Álvarez-Jiménez M, González-Blanch, C, Crespo-Facorro, B et al. Antipsychotic-Induced Weight Gain in Chronic and First-Episode Psychotic Disorders. *CNS Drugs*. 2008. 22, 547–562. https://doi.org/10.2165/00023210-200822070-00002
- 29. Jones R, Major B, Fear C. Schizophrenia in a primary care setting. *Curr Psychiatry Rep.* 2015. 17(10):84
- 30. NHS England. 2023. Quality and Outcomes Framework Guidance for 2023/2024.

- 31. NHS England. Expanding Our Workforce. https://www.england.nhs.uk/gp/expanding-our-workforce/ (accessed 23.01.24)
- 32. Nilforooshan R, Weston L, Sachdeva D et al. What information do general practitioners expect in letters from mental health services? *London J Prim Care*. 2009. 2(1) 43-45, DOI: 10.1080/17571472.2009.11493241
- 33. Onwumere J, Shiers D, Chew-Graham CA. The needs of carers of people with psychosis in primary care. *Br J Gen Prac*. 2016. 66(649): 400-401. DOI: 10.3399/bjgp16X686209

Tables and Figures

Table 1 – SU demographics

Participant ID	Gender	Age	Ethnic background	Living circumstances	Employment
					Stay at home
SU1	Female	32	White British	Lives with partner and children	parent
301	Terriale	32	Willie Bileisii	Elves with partner and children	parent
SU2	Female	28	White British	Lives alone	Unemployed
SU3	Female	28	White and Black Caribbean	Lives with partner and child	Part-time employed/student
			Mixed/multiple	4.74°	
SU4	Female	26	ethnicity	Lives with father	Unemployed
SU5	Female	43	White Polish	Lives with partner and child	Full-time employed
SU6	Female	28	White British	Lives with father	Unemployed
SU7	Female	61	White British	Lives with partner	Unemployed
SU8	Female	57	Black Caribbean	Lives alone	Unemployed Full-time
SU9	Male	43	Black British	Lives with partner	employed
SU10	Female	64	White British	Lives with partner	Unemployed
SU11	Male	25	White British	Lives alone	Full-time employed
SU12	Male	43	White British	Lives with partner and children	Full-time employed
SU13	Male	45	White British	Lives alone	Unemployed

Table 2 – Carer demographics

Participant ID	Gender	Relationship to person with Psychosis	Age	Ethnic background	Employment
CAR1	Male	Brother	25	Asian	Full time employed
CAR2	Male	Friend	26	Black British	Part time employed

	1	1	1 1	1	
CADO	Famala	Nicco		Indian	Part time
CAR3	Female	Niece		British	employed
CAR4	Female	Mother		White British	Retired
CAN4	remale	ivioniei		White	Full time
CAR5	Male	Husband		British	employed
				Black	Part time
CAR6	Male	Grandchild	23	British	employed
				White	Part time
CAR7	Female	Mother	1 1	British	employed
				White	
CAR8	Male	Partner		British	Retired
		Former			Full-time
CAR9	Female	partner	45	Bangladeshi	employed
				White	Part-time
CAR10	Female	Mother	45	British	employed
Table 3 – 0	т раск				
Participant	6	Years as	Size of		
ID	Gender	GP	practice	Geography	
GP1	Female	10	25k	Inner city	
GP2	Male	5	26k	Urban	
		5 years as			A.V.
GP3	Male	partner	20k	Rural	
GP4	Female			×3	
	remale	25	n/a	n/a	
	remale	25 11 years	n/a	n/a	
GP5	Male	25 11 years as partner	n/a 14k	n/a Suburban	

Table 3 - GP background

Participant		Years as	Size of	
ID	Gender	GP	practice	Geography
10	Gender	- Gi	practice	Geography
CD4	F	10	251	La caracteria
GP1	Female	10	25k	Inner city
GP2	Male	5	26k	Urban
		5 years as		
GP3	Male	partner	20k	Rural
				/D
				- / Y
CD4	F 1 .	25		
GP4	Female	25	n/a	n/a
		11 years		
GP5	Male	as partner	14k	Suburban
			C	
GP6	Female	19	14k	Urban
			7	
GP7	Female	13	10k	Semi-rural
5. 7	remaie	13	101	Jenn rarar
CDO			21.	I I also a co
GP8	Female	4	3k	Urban

Table 4 – EIP practitioners/manager/commissioner background

Participant		
ID	Gender	Job title
>		
HCP1	Female	Clinical Lead, Early Intervention in Psychosis
HCP2	Female	EIP Team Manager
НСР3	Female	EIP Team Manager
HCP4	Female	Care co-ordinator/Mental Health Nurse
HCP5	Male	Consultant Psychiatrist

HCP7	Male	Advanced Clinical Practitioner/Social Worker
НСР8	Female	Care co-ordinator/Mental Health Nurse
	Female	Community psychiatric nurse
HCP9	Male	Consultant Psychiatrist
HCP10	Male	Consultant Psychiatrist
HCP11	Female	EIP Team Manager
HCP12	Male	Psychologist
HCP13	Male	Case manager
HCP14	Male	Psychologist Case manager EIP Team Manager Clinical Nurse specialist EIP Team Manager Principal Psychologist Principal Psychologist
HCP15	Female	Clinical Nurse specialist
HCP16	Female	EIP Team Manager
HCP17	Male	Principal Psychologist
HCP18	Female	Principal Psychologist
HCP19	Male	Community Psychiatric Nurse
HCP20	Female	Clinical Lead, Early Intervention in Psychosis
LICD24	Famala	Courses and instant Adapted Hardth Numer
HCP21	Female	Care co-ordinator/Mental Health Nurse
HCP22	Male	Community Psychiatric Nurse
HCP23	Female	Peer support worker
COM1 COM2	Male Male	Commissioner - Senior Programme Manager Commissioner - Senior Programme Delivery Lead