NEL Personalised Cancer Care Delivery Group

Improving Cancer Journeys Learning Programme

25 Jun 2024

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A growing and inequitable problem

Problem: People affected by cancer do not have equitable access to the practical, emotional and physical support they need to progress their clinical cancer treatment and keep their lives on track. Those who feel the biggest impact of this lack of support also tend to be those with the greatest need.

People living with cancer need more information and confidence to help them navigate care and access support, so they can be encouraged to get a diagnosis earlier and stay in treatment.

The Improving Cancer Journeys learning programme

Aim: To increase access to practical, emotional and physical support for people diagnosed with cancer, and the people important to them, so they can stay in treatment and keep their lives on track.

Implementation

- Accelerate the implementation of interventions across three ICSs
- Understand what good personalised holistic support looks like – what interventions work consistently well and what needs to be adapted to local needs?
- Give systems the tools and evidence to unlock transferability of ICJ to other sites.

Evaluation

Build on the evidence base for personalised care through:

- Outcome evaluation: Do the interventions help people to complete their cancer treatment?
- Process evaluation: How did implementation work in practice and the experiences of patients, families and carers, and staff?
- Economic evaluation: What are the costs of implementing ICJ?

Building plans based on the principles of ICJ

What it is

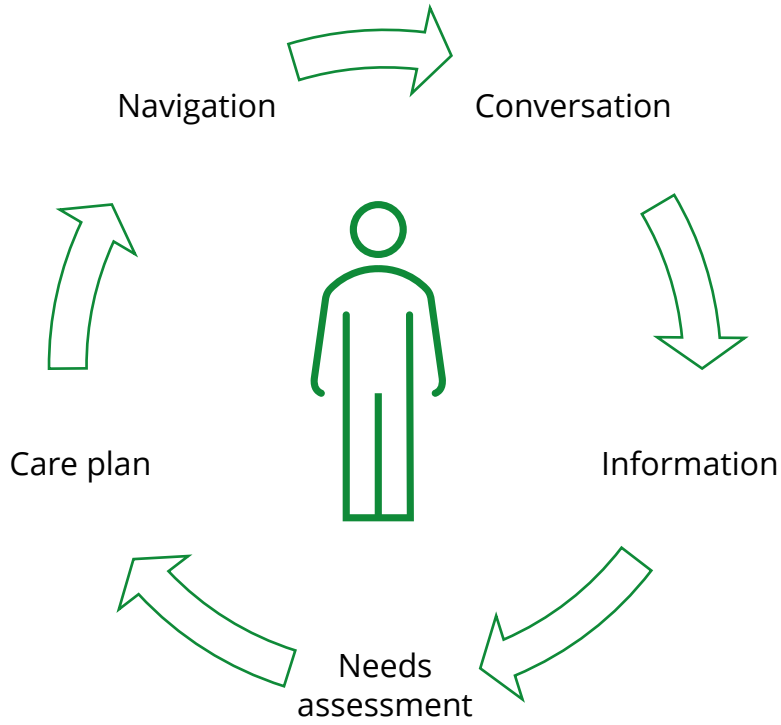
- Support is systematic and proactively offered to everyone diagnosed with cancer
- An opt-out model of referral
- Every concern has a route into a support service (clinical, financial, social, etc.)

How it is delivered

- Place-based non-clinical care model with service based in an out-of-hospital setting
- Built locally through co-design with communities and people with cancer
- Built on a foundation of community Support and Information services
- Supported by local community assets

What is needed

- Senior leadership buy in and system readiness as essential enablers
- A co-ordinated approach across settings with data sharing in place
- Data to drive better quality decisions and service improvements



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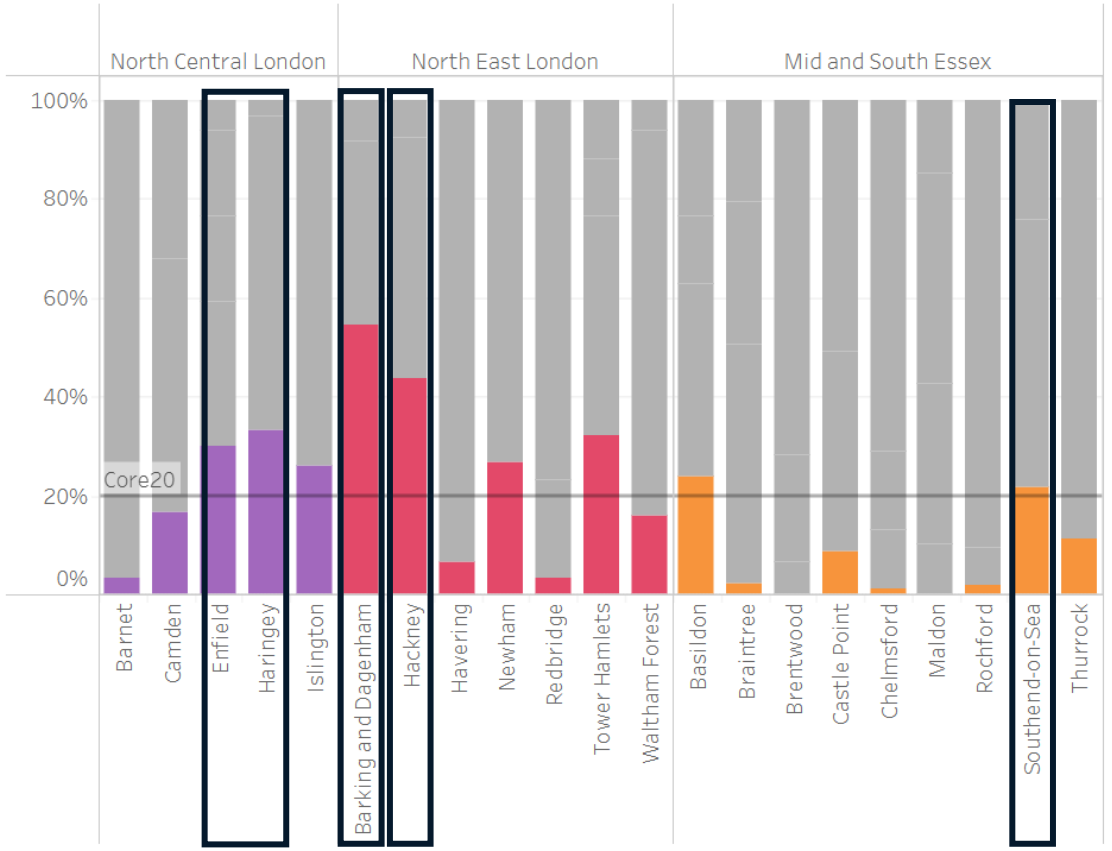
Why Barking and Dagenham and Hackney?

Site selection focussed on population need

- We are starting with the hospitals and boroughs that have the **highest levels of deprivation**, to have the greatest impact.
- Sites (and their corresponding populations) were selected based on the following criteria:
  - More than 20% of the population in the most deprived decile
  - A critical mass of cancer activity across tumour groups
  - A critical mass of patients from 1-2 local boroughs
  - Senior level commitment to participation
- In the first year, we seek to understand the equality implications of personalised holistic support in detail, to ensure that it **can make a significant contribution to reducing healthcare inequality**.

Percentage of the population in each local authority that is in the most deprived 20% of the national population

Source: English indices of deprivation 2019



Where are we now?

Reviewing the current-state pathway

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Key elements of the pathway

During the discovery phase, UCLPartners has built an illustration of current pathways, based on discussions with multiple system stakeholders, looking at the following elements:

Identification
- How do we know which patients needs a holistic conversation and how are they tracked?

Routes into the service
- How do patients access the service?

The Conversation
- How do patients share their concerns, and with whom?

Support
- What support is offered and how is it accessed?

Follow-up
- How and when can they 're-enter' the service?

System enablers

Workforce:
Training, Competencies, Development, Support

Systems:
IT interoperability, Information sharing, Ways of Working

Partnership:
Host organisation(s), System collaboration

Governance:
Information governance, Decision-makers, Funders

Current pathway

*"They are a big chunk of your day, they're so worthwhile, but they can be incredibly time consuming and that is **more the admin side than the actual spending time with patients which is a shame**."*
– Acute staff member

	Identification	Routes into the service	The Conversation	Support	Follow-up
Pinch Points	• Patients who are diagnosed **outside the Trust or on the ward** are harder to identify • Patients coming from Essex for their diagnosis/treatment • Difficult to track those who don't get treatment	• The timeline and offer for HNAs is **heavily reliant on the presence of CSWs** and on activity within the tumour group • Often patients will decline a HNA because they are not sure what it is and think they are fine/don't need support	• Challenge discussing top concerns • HNA documentation as a tick-box exercise • Language barriers and other challenges such as SMIs and brain-related health conditions • Filling out the HNA can be stressful for some patients, especially at the start of treatment	• Have patients from Essex who they cannot refer/signpost as not local • Patients' perceptions of what they're entitled to • **Waiting times** for services, especially welfare advise • Self-referral for counselling is a struggle for patients • CNS need to review HNA before it's locked which can take time	• Lack of capacity or time to follow-up with patients
Bright spots	• The use of **databases and spreadsheets** to track patients	• **Good communication** between CNSs and CSWs • Sending information to the patient ahead of a call either given at clinic or sent via post • CSWs calling the patient to offer the HNAs	• CSWs use **a range of approaches for the conversation** including a structure/template or an informal conversational approach • HNA clinic slots for the CSW • Combination of F2F and over the phone appts – **patient preference**	• On-site living with and beyond cancer team considered a huge asset • **CSW try and do as much as they can for patients,** including booking them onto groups/services and informing them that they're not obligated to go.	• One team does monthly courtesy calls for all patients which they describe as a 'patient-led service' • **Designated staff to do different HNAs at different periods** • Patients are provided with contact details for their entire cancer team so they can get in touch

Current pathway – reflections from the group

Routes into the service

- **Need more information about why patients might decline HNAs** – are there specific groups that more frequently decline the offer?
- Reliant on emails from CNSs to CSWs – what if a CSW isn't there?
- The use of **phrases such as HNAs/CCRs could be a barrier** for patients as they might not understand what the phrases mean and therefore why they need to take up the offer. Additionally, patients might not realise they have had these conversations with their healthcare team because of the language/approach used.
- Feedback from patients that the call they received about the **HNA offer sounded like a sales pitch**.

The conversation

- While staff agree that the conversation is vital, there are **significant administrative challenges** with HNA/care plan documentation.
- **Language barriers and digital exclusion** are key considerations.
- Important **to set expectations** about what support is available.
- It's vital to **focus on empowering** patients.
- The concerns checklist should ask about worries/concerns in the last seven days, to help focus the conversation on the patient's most pressing concerns.
- The types of concerns that are mentioned are **dependent on who patients speak with** – CNS, consultant, CSW etc.

Support

- **A care plan can be confused with a treatment plan (clinical).**
- A welfare service is available via the Trust.
- Consider **long waiting times** for counselling services.
- Referrals for counselling are to the Macmillan BUPA service.
- Care plans are not translated into other languages for patients.

System enablers

	Workforce	Systems	Partnership	Governance
Pinch Points	• **Emotional/psychological support for CSWs** • Lack of capacity (not enough CSWs or some tumour groups have none) • Some CSWs reported not having any formal training	• Staff reported the eHNA link only allows access once. Some patients are unable to return to completing the form because the session timed out. • Staff feel as though there should be **one system for HNAs** – pulling into Somerset is seen as an additional admin burden • Staff are constantly assessing patient's needs but may not be documenting them as eHNAs and are documenting them in other ways on the EPRO. • The admin burden of undertaking HNAs	• Currently no interaction between the acute team and social prescribers in the community	
Bright spots	• **CSW as the face of the tumour team** • **Admin support** for booking appointments • Living with and Beyond Cancer Team • **Social prescribers** based in local authority • 1 day/week dedicated for admin	• **Joy system** for communicating between teams • Primary care report receiving some care plans from some tumour groups • Care plans are emailed to the GP automatically • Trust undertakes a HNA audit at the end of the year • One team reports having **all local GP practices on their database** and have received confirmation of receipt of care plans	• The LWBC team is linked to the community and has various services in their newsletter • Copying consultants in emails so they have a view of what's happening	• HNA appointments being listed as **outpatient clinics** helps with funding and recording of activity.

System enablers – reflections from the group

Workforce

- Need to ensure **staff feel valued** and that there are opportunities for development and progression.
- Need to review induction and job planning for CSW new starters
- Managers for CNSs might not specialise in cancer and therefore **may not be able to adequately champion** this work and/or support CNSs to undertake it.
- Important to have **tumour-specific cancer support workers**.
- NELCA is overseeing the implementation of the ACCEND framework, which aims to provide transformational reform for the career pathways and associated education, training, learning and development opportunities for the workforce providing care to people affected by cancer.

Systems

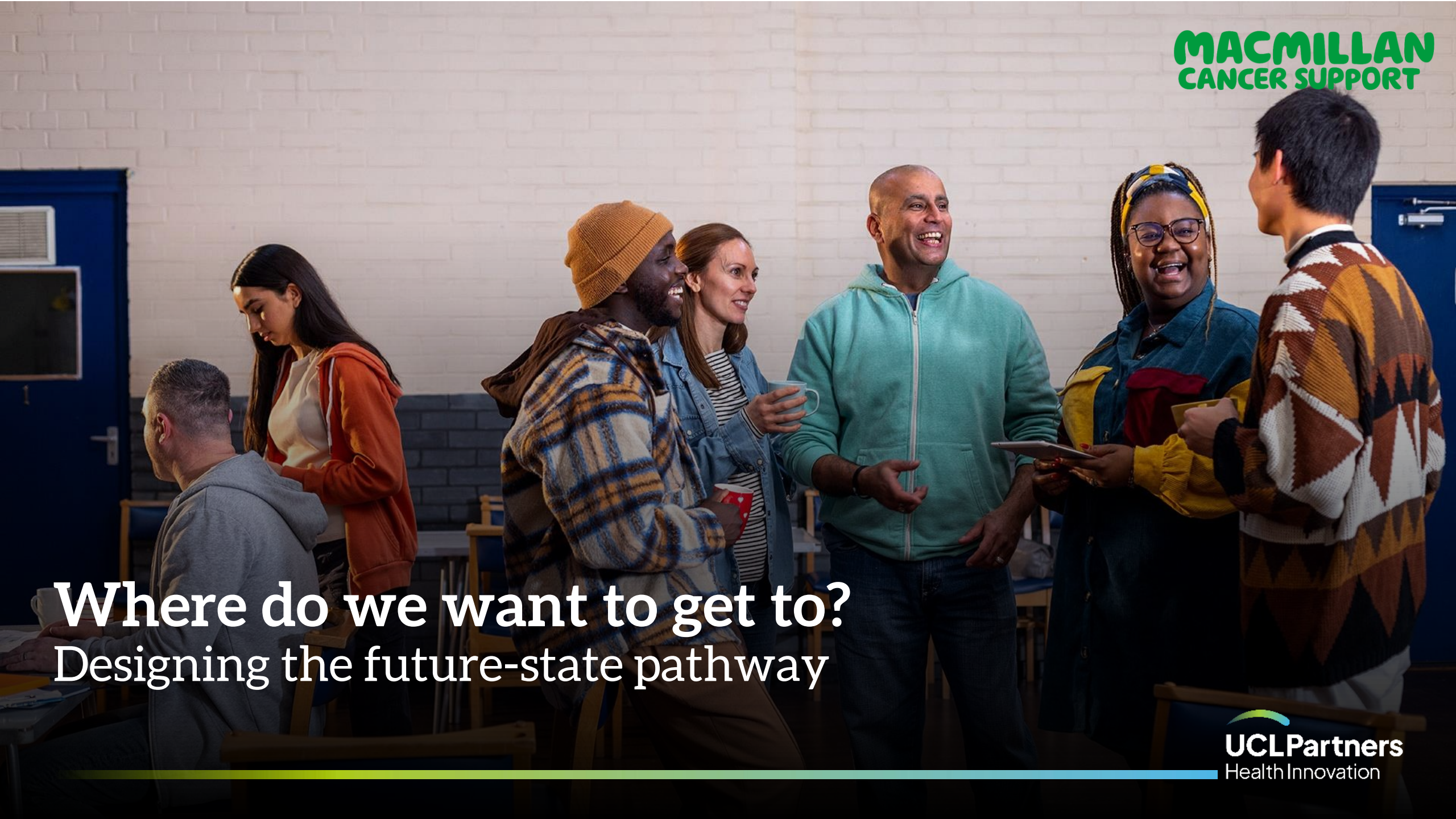
- There needs to be more work done to **collect data on why patients decline HNAs**. Currently, the PCC team are looking at cancer activity compared to HNA uptake to compare groups and understand who might not be taking up the offer.

Partnership

- Need to be clearer about **expectations across the system**.
- Currently, there is **limited awareness of what support is available** in the community.
- Need **to raise the profile of PCC** within teams across the system.

Governance

- Challenges with funding and sustainability.



Where do we want to get to?

Designing the future-state pathway

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Group discussion about the programme aim

ICJ Learning Programme aim: To increase access to practical, emotional and physical support for people diagnosed with cancer, and the people important to them, so they can stay in treatment and keep their lives on track.

B&D aim: To increase access to practical, emotional, spiritual, and physical support for people diagnosed with cancer, and the people important to them, so they can stay in treatment and keep their lives on track.

Considerations

- Does 'stay in treatment' exclude people who only have surgery?
- Prehabilitation, rehab are key parts of treatment
- Patients understanding this offer as part of their cancer care and not 'nice to have'

Group discussion about the local ambition for B&D

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What does this look like for Barking and Dagenham?

- Setting the relationship from the beginning with the family as well
- Workforce across the system and being a part of everybody's business
- Identifying community assets e.g., smoking cessation
- Patient empowerment and engagement in navigating their health
- Early patient communication
- Avoiding crisis

What are the most pressing challenges?

- Reaching underserved communities
- Getting back to work/time off to attend appointments
- Different/inconsistent information
- Digital inclusion
- Childcare and other caring responsibilities
- IT infrastructure

Where will we have the most impact?

- Black African and Caribbean
- Asian community
- Late presentations

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Next steps

Produce a learning report

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- Current pathway visualisations
- Insights on brights spots and pinch points
- Stakeholder and asset maps
- Evaluation framework

Establish a local steering group

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- Agree roles of different organisations
- Named application lead, SRO and Finance lead

Analyse baseline data and patient insights

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- Patient survey and focus group insights shared
- Baseline quantitative data analysis

Co-produce an implementation proposal

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- Stakeholders to review proposal
- Submit proposal to Macmillan

Does this work align with any work you're doing?

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