Transformation Partners
in Health and Care

“Uncertainty breeds distress”: Exploring the psychological impact of the cancer diagnostics pathway

FINAL REPORT

21 March 2023
Liz Price, Senior Programme Manager
Transforming Cancer Services Team (TCST)

Transformation Partners
in Health and Care

NHS

Executive summary

Project overview

North Central London (NCL) Integrated Care Board (ICB) identified psychological harm as a priority in 2021, including on diagnostics pathway. Asked TCST to undertake a project for NCL, with the rest of London. Anticipate findings to be of relevance and useful everywhere.

Project scope was initially about cancer waits and delays, and factoring in psychological harm alongside clinical harm reviews - with the aim of getting people the right support as quickly as possible.

Methodology - literature scan, learning from St George's psychologically informed RDC pathway, 12 focus groups, ½ day workshop, stakeholder survey, 10 engagement meetings with NCL and Pan London groups.

Following a scan of research and some early focus groups, scope was altered to encompass all people from the point of 2ww referral onwards to the start of first treatment – with the aim of preventing distress and promoting adjustment as early as possible.

Project learns from the Macmillan funded TCST psychosocial programme (2017-20).

A pragmatic approach was taken, rather than blue sky thinking. System wide recognition that workforce, in all areas, is a major barrier to blue sky thinking at the moment.

Project takes a multi-disciplinary view, with the following involved at each step:

patients and carers :
primary care
psycho-oncology
cancer nursing
cancer support workers
oncology and surgery

7 Principles for primary and acute care services

1. Every *conversation* counts.
2. Consistent, efficient and clear information builds trust and reduces distress.
3. Provide a named contact person on receipt of referral.
4. Make time to explore the emotional impact of the referral, diagnostics, and treatment process.
5. Manage expectations by being clear about what we do know, and what we don’t.
6. At the time of booking appointments, proactively identify needs and arrange reasonable adjustments.
7. Offer psychological interventions for families/partners too.

High level workplan (2023-26)

Time frame	Tasks	Lead	Interdependencies
Short term April 23- Mar 24	• NCL to prioritise CUP, MUO and NSS MDTs for a pilot project in one NCL Trust, using learnings from St Georges RDC pathway	NCLCA	• Trusts & PCNs
	• Update 2ww Patient Information Leaflet (including info for families and unpaid carers) • Develop practical information about diagnostic pathways for patients & families • Develop standard process to send urgent alert emails to GP Practice inbox regarding psychological red flags	TCST + Alliances	• Patient Advisory Groups • Trusts & PCNs • Pathway Boards

Medium term
Apr 23 - Mar 25
	• Psycho-oncology provision – workforce planning to encompass extension of services to include support for families
	• Enhanced communications training & supervision:
	  • Pilot enhanced communications training for hospitals' Access teams
	  • Map access to supervision for Level 2 trained professionals
	  • Scope access to supervision for non-clinical professionals who work with patients on cancer diagnostic and treatment pathways
	• Secure access to a range of services so that suitable reasonable adjustments, from the time of booking first diagnostic appointments, can be put in place for patients (and family members where required).
	• Identify named points of contact on cancer diagnostic pathways:
	  • non-clinical roles within hospital teams (eg access teams, diagnostic services) as a named contact person from receipt of referral.
	  • MDTs to identify routes to accessing a cancer key worker as soon as high risk of malignancy is known.
	  • Develop a checklist/top tips to enable other services to implement this approach/
		NCLCA	• Trusts
			• NHS London region workforce team (previously HEE)
			• Planned care & diagnostic programmes

Long term Apr 24- Mar 26	• Secure funding and workforce to ensure sufficient psycho-oncology is available across NCL - to support cancer patients, their families and deliver essential indirect work.	Alliance	• ICB • Trusts
	• Scope the need and capability of a patient support line for people on diagnostic pathways	TBC	• Planned care & diagnostic programmes

Short term priority actions (2023/24)

Deliverable	Tasks	Lead	Interdependencies
Pilot SGUH RDC psychologically informed pathway in one Trust (CUP, MUO and NSS pathways)	• Redesign CUP, MUO and NSS pathways – from Primary care referral through to diagnosis confirmed/ruled out • Revise NCL RDC/NSS referral form to encompass broader questions on things that may impact that person's ability to engage with the pathway (as per London 2ww forms) • Triage to include psychosocial aspects • Secure sufficient psycho-oncology to support revised pathways • Develop psychosocial referral routes to other services eg NHS Talking Therapies, Pain services etc.	NCLCA	• Trusts & PCNs • NHS Talking Therapies
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Develop practical information about diagnostic pathways for patients & families	• Develop 'once for London' diagnostic pathway documents designed for patients and families – easy to read, in multiple formats and languages. • Web based so easily updated and integrated on Trust websites and Primary Care systems.	TCST/ Alliances	• Common cancers: ○ use Best Practice Timed Pathways ○ co-design remaining ones (including those designed for delegation) between Alliances' pathway boards and patient partners • Rarer cancers (where pathway boards don't exist) – co-design between TCST, clinical leaders within each Alliance and patient partners with rarer cancers. • Alliances to support Trusts and PCNs to embed locally, eg accompanying 2ww information leaflet, Access offices sharing info.
Develop standard process to send urgent alert emails to GP Practice inbox regarding psychological red flags	• Develop Standard Operating Procedure for all Trusts: a) brief summary of the concern b) recommended actions for primary care c) notification that patient has been referred into psycho-oncology (or other service) d) contact name in acute team for GP to call and discuss • Develop "PCN SOP" for safety netting, coding and responding to the alerts.	Alliances	• With Trusts and PCNs, develop SOPs and embed change of practice

The NCL Cancer Programme Board is asked to support the following recommendations:

1. Ensure clinical psycho-oncology is represented within NCL cancer projects, programme governance and decision making.
2. Endorse all principles - Ensure NCL commissioning and service improvements factor in both this set of principles (see next slide) and those contained within TCST Guidance 2020.
3. Ensure that actions and principles taken forward from this project align with national cancer deliverables and local cancer alliance plans, particularly with regard to early and faster diagnosis, personalised cancer care and closing the gap in psycho-oncology provision in NCL.
4. Endorse high level workplan (spanning 2023-2026).
5. Endorse priority actions for 2023/24:
    a. **NCL to prioritise CUP, MUO and NSS MDTs for a pilot project in one NCL Trust, using learnings from St Georges RDC pathway**
    b. **Recommend the following priority actions for a coordinated pan London design & delivery:**
        - **Update pan London 2ww Patient Information Leaflets and evaluate using psychologically informed methodology**
        - **Develop practical information about diagnostic pathways for patients & families**
        - **Develop standard process to send urgent alert emails to GP Practice inbox regarding psychological red flags**

Project

- Context
- Aims & methodology
- Literature scan
- St George’s RDC pathway
- Focus Groups
- Half day workshop, survey & engagement meetings

An opening word - from a patient partner

“Recognising psychological harm and working to reduce it needs to be as integral to cancer diagnosis, treatment and aftercare, in the same way that work to reduce physical harm is.

“At the moment the approach is patchy and, as a patient, it can feel like the ball is firmly in our court to both identify the support we need and to then find out how to access it. It can feel like a battle to get support at the precise time when having the emotional resilience to do this is at its lowest ebb.

“Having these principles not only gives those in healthcare the framework to deliver psychological support but also forms a commitment to the patient that the need for support is embedded in their cancer pathway.”

Cancer Patient Partner, North Central London

Context

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Cancer waits backlog!

Project **scope was initially about cancer waits and delays**, **and factoring in psychological harm** alongside clinical harm reviews - with the aim of getting people the right support as quickly as possible.

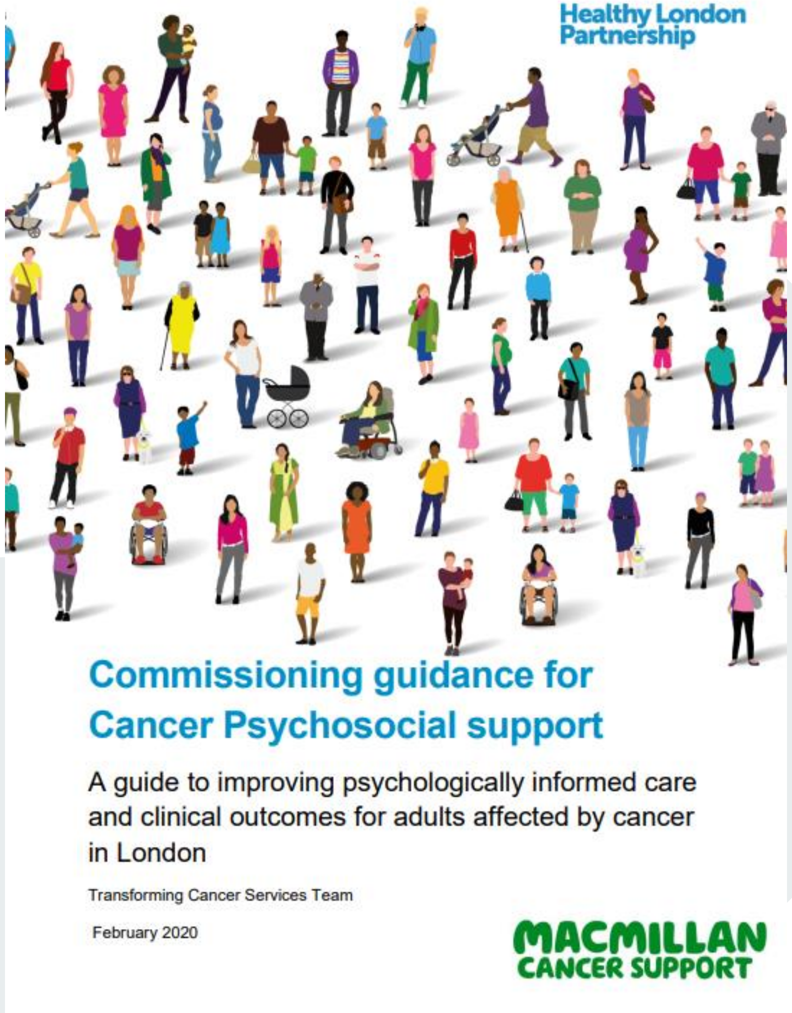
Following a scan of research and some early focus groups, **scope was altered to encompass <u>all</u> people from the point of 2ww referral onwards to the start of first treatment – with the aim of preventing distress and promoting adjustment as early as possible**.

A **pragmatic approach was taken**, rather than blue sky thinking. System wide recognition that workforce, in all areas, is a major barrier to blue sky thinking at the moment.

Project took a **multi-disciplinary view**, **with** the following involved at each step:

1. **patients and carers :**
2. **primary care**
3. **psycho-oncology**
4. **cancer nursing**
5. **cancer support workers**
6. **oncology and surgery**

Project builds on TCST's pan London psychosocial programme (2017-20), funded by Macmillan



Healthy London Partnership

Commissioning guidance for Cancer Psychosocial support

A guide to improving psychologically informed care and clinical outcomes for adults affected by cancer in London

Transforming Cancer Services Team

February 2020

MACMILLAN CANCER SUPPORT

Project aims & methodology

Aims

1. Explore 'psychological harm' caused by waiting for diagnostics and first treatment
2. By understanding the impact of psychological harm, produce recommendations to improve patient care.

Methodology

1. **Steering group established**, led by TCST and NCL Integrated Care Board, as this project was initiated and sponsored by North Central London.
2. Conducted a **literature scan**, **12 semi-structured focus groups** and **half day workshop**.
3. Took learnings from **psychologically informed Rapid Diagnostic Centre pathway** at St Georges Hospital, South West London
4. Engagement with a variety of stakeholders:
   - **a.** **Survey** for focus group participants, workshop attendees and stakeholders from key pan London and NCL groups – launched Mon 30th Jan and closed Fri 10th Feb.
   - **b.** **Met with** more than 10 (and counting) **pan London and NCL groups** to discuss the work.
   - c. All engagement **focused on** a draft set of **principles, prioritising vulnerable group/s** and **key actions.**
5. Engagement **feedback was assimilated** to refine the principles, identify an MDT pathway and prioritise realistic actions over next three years.
6. A **final suite of recommendations** at the NCL Cancer Programme Board on 28 March 2023 for sign off.

Findings – from the literature

- **Physical Activity (lower levels)** indicated likelihood to suffer depression during treatment
- **Illness perception** – such as social support, physical symptoms and patient satisfaction is influenced by these factors (illness perception then links to levels of distress)
- **Screening for distress** and offers of subsequent treatment does not necessarily equate to reductions in distress
- In one study - changes in mindfulness practice did not necessarily equate to change in acceptance

So what does the literature tell us that's needed?

Communication and engagement between patients, family and healthcare workers valuable to positive engagement and potential outcomes and satisfaction in care on all pathways. All improved patient retention on pathways.

1. **Acknowledge** psychological aspects **early**
2. Discuss **coping** strategies with **patients and families.**
3. **Support from healthcare workers** to schedule appointments and provide trust in treatment and care
4. Psychological interventions should be **offered to those at high risk** of developing psychological distress
5. A **clear referral pathway from pre-diagnosis to diagnosis** for both treatment and concurrent psychological care is helpful, both for patients and also their family members guiding them through stages of diagnosis
6. **Adaptions by patients to treatment** is key to concurrent depressive symptoms e.g traits such as resilience, optimism, ability to comprehend illness and perceived ability to cope with trauma

St George’s Rapid Diagnostic Service (South West London)

An example of a psychologically informed pathway, from the point of the GP referral onwards.

Key stages of the pathway include:

1. RDC referral form:
    - **The question “is there any history of mental health which may impact upon patient engagement?”**
    - **Requires a Yes/No answer, and “if yes, please give details”.**
2. Triage with the Advanced Nurse Practitioner – includes a list of questions about physical and psychosocial symptoms. Patient may be referred to psycho-oncology at this point.
3. Multidisciplinary team conversations – Psycho-oncology may become involved when patients don’t attend appointments or other evidence that patient may be finding it difficult to engage with the appointments.
4. Consultant review – another appointment where patient may be referred to psycho-oncology. Patients may be more distressed/vulnerable at this point, rather than at triage.
5. End of RDC pathway:
    - **when the patient doesn’t have cancer, they may be referred elsewhere (eg IAPT, chronic pain services etc)**
    - **when patient is diagnosed with cancer, they may be referred to psycho-oncology here too.**

NB: Referral into psycho-oncology on RDC pathway = up to 60 minutes appointment. Includes a psychological assessment +/- short therapeutic intervention

Findings – from the focus groups

Twelve focus groups and interviews held by Liz Price (Transforming Cancer Services Team) and Claire Cassidy (NCL Cancer Alliance) during summer 2022. There were 36 participants overall from the aforementioned six groups.

> *"How do you know when the distress is harm? It's almost an ethical question, isn't it?"*

Assessing psychological harm is complex and not comparable to assessing clinical harm on a cancer diagnostics pathway.

NHS services should be pro-active, personalised and prioritise minimising distress and promoting adjustment for both patient and family.

Through thematic analysis of the transcripts, five overarching themes were identified:

1. Reactions to the terminology of "psychological harm" and "distress" – prefer distress
2. Family dynamics during diagnostic phase
3. System issues contributing to distress/harm
4. Measuring/detecting harm and distress – acute care
5. Measuring/detecting harm and distress – 2ww referrals

> *"I want honesty and I'm a nerd, so I like to know all of the information. The more I know, the more calm I am about what's going on. And because I'd rather be told the truth than someone dressing stuff up and saying, no, everything's going to be fine and whatever. No, it's cancer. It's not a cut knee and I'd rather know the truth. What's actually going to happen? And then I can prepare for it".*

Outputs – from the workshop, survey & engagement meetings

“From a patient's point of view, what I can gather from my focus group, is the need to start with small, few changes that could make a big difference - more than think to make massive changes that could be very unsettling to process for patients too.”

“We have to ensure we provide equal support to families with children as well as adults.”

“There is a great sense also we need to listen to patients' opinions, as professionals might sometimes overlook what really matters to them.”

“This is a great project with the potential to make real change in the future.”

1. A set of principles were co-developed and tested.
2. A small list of tumour specific pathways were proposed to prioritise – to develop one of these into a psychologically informed pathway in NCL and pilot in one Trust.
3. A very long list of suggested ideas was collated and tested with the following parameters:
    - *Would it require a lot of funding?*
    - *Would it require a lot of time?*
    - *Does it already exist/ could it be adapted?*
    - *Would it be easy to deliver?*
4. Initiated regional conversations with psycho-oncology clinical leads, lead cancer nurses forum and CSW Community of Practice - re whether additional training and supervision is needed for CSWs regarding a) the burden of emotional support of patients they are holding and b) their own self care.

A word - from a consultant

“Pilot a service that is designed for those most vulnerable as you see it in the population group.

“Could you demonstrate that not only that pathway is ideal for those who are most vulnerable, but once it is designed it captures everyone by nature of its design.

“With that ideal pathway, could you demonstrate that not only it is ideal for those vulnerable, but it’s also ideal for everyone else. Is it just as efficient, safe and effective for everyone?”

Head & Neck Surgeon, West London

Recommendations

The NCL Cancer Programme Board is asked to support the following recommendations:

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7 Principles from primary and acute care services

1. **Every *conversation* counts** - balance bite sized, manageable information along each step with clarity about what we do know AND what we don't know at each step of the pathway. This bite sized information has to be relevant to the person in front of the staff member. Primary care should use the word 'cancer' with the patient when they are making a 2ww referral (to rule cancer out) – not using the word can cause greater distress later. We need to think beyond the patient and consider the needs of families too.
2. **Consistent, efficient and clear information builds trust and reduces distress** - Staff need to build relationships with patients and families to have complex conversations. Communication systems need to be reliable and timely between patients and all relevant NHS services. Information should be provided in different formats and different languages, so that it is appropriate for individual patients and family members. These aspects are also key to informed consent and shared decision making.
3. **Provide a named contact person on receipt of referral** – It is important that patients receive contact details of a named point of contact for any questions or concerns. This could be a pathway facilitator, navigator or support worker. For those patients where a high risk of malignancy is identified, a cancer key worker should be identified straight away so that they can support the person as early on in their cancer pathway as possible.
4. **Make time to explore the emotional impact of the referral, diagnostics, and treatment process** - with patients from the very start. Let families know they can ask questions and have private conversations whilst respecting patient confidentiality.
5. **Manage expectations by being clear about what we do know, and what we don't** – clarify what people understand about waiting; distress is understandable and expected when there is uncertainty; about the pathway itself (being clear on what is known and what is unknown at each point). It's important that we include families/significant others in how we support others with the emotional impact of cancer and managing expectations.
6. **At the time of booking appointments, proactively identify needs and arrange reasonable adjustments** – translation services, physical access, hearing & sight impairments, those with complex mental health needs etc. This includes sharing of information between primary and acute care teams, and mental health services and primary care/cancer team (where appropriate and with patient permission). Consider the role of hospital and third sector volunteers in supporting patients need reasonable adjustments.
7. **Offer psychological interventions for families/partners too** - Psycho-oncology services need adequate resourcing to provide this much needed work, including but not limited to bereavement/anticipatory grief support to family members. Psychologically informed care means that the emotional impact of cancer on families and significant others is considered across the whole pathway, alongside the needs of patients.

High level workplan (2023-26)

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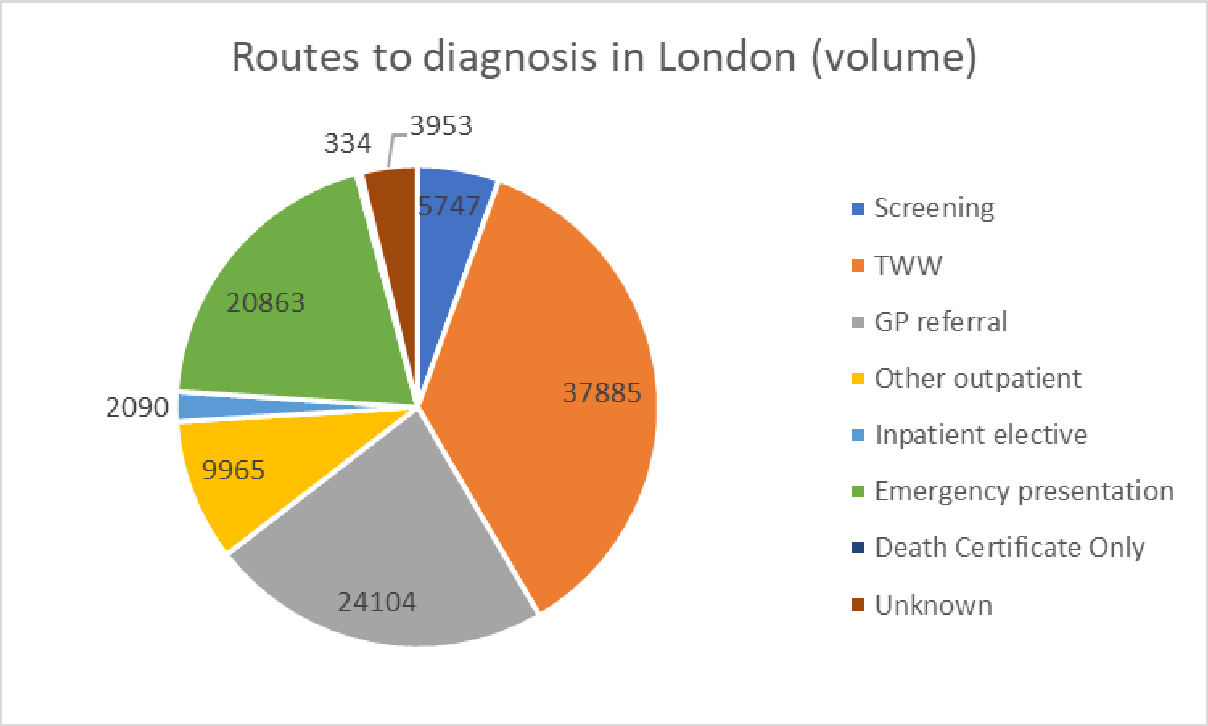
Develop standard process to send urgent alert emails to GP Practice inbox regarding psychological red flags	- Develop Standard Operating Procedure for all Trusts: a) brief summary of the concern b) recommended actions for primary care c) notification that patient has been referred into psycho-oncology (or other service) d) contact name in acute team for GP to call and discuss - Develop "PCN SOP" for safety netting, coding and responding to the alerts.	Alliances	- With Trusts and PCNs, develop SOPs and embed change of practice

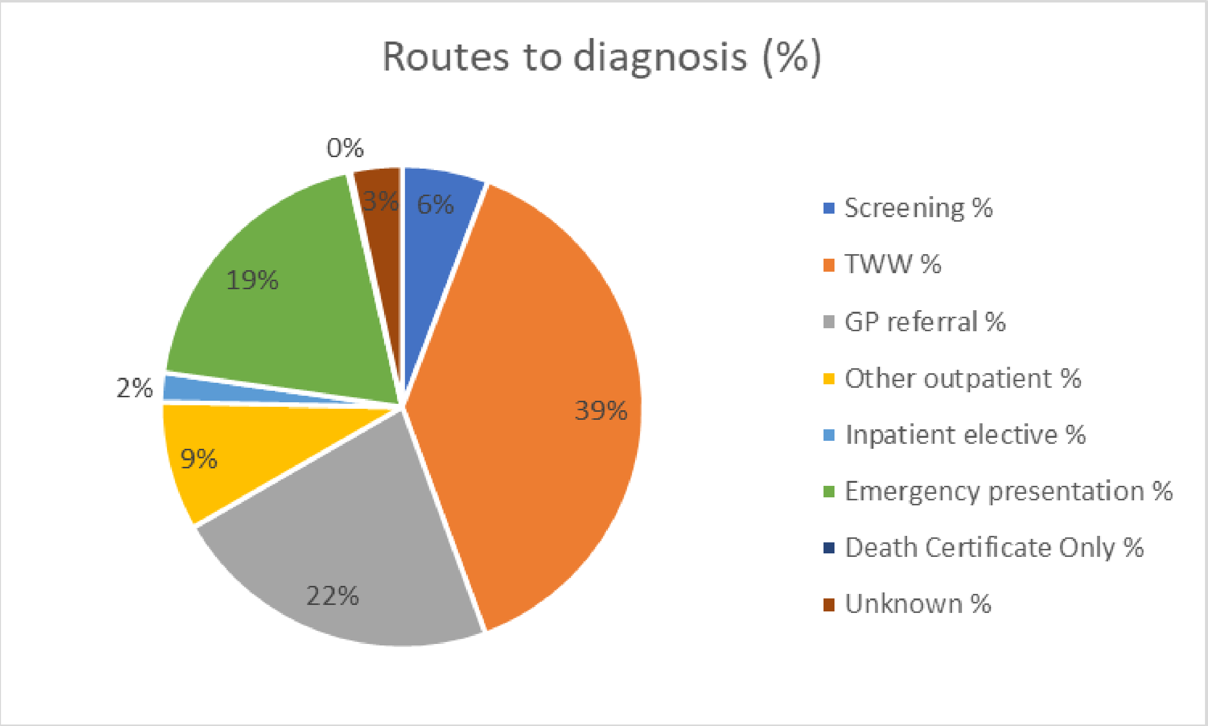
Appendix A:

NCL and London context

Routes to diagnosis in London

Volume and percentage of diagnoses of all malignant cancers (excluding non-melanoma skin cancer) in London - 2018

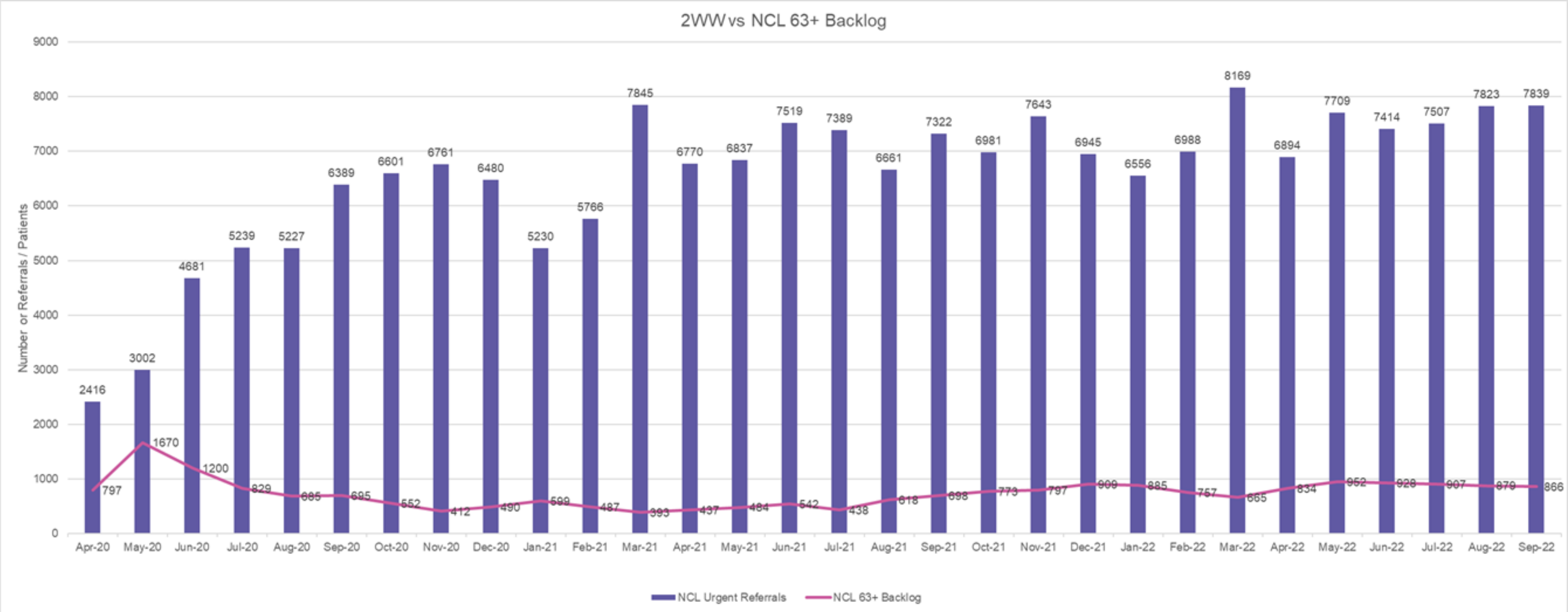




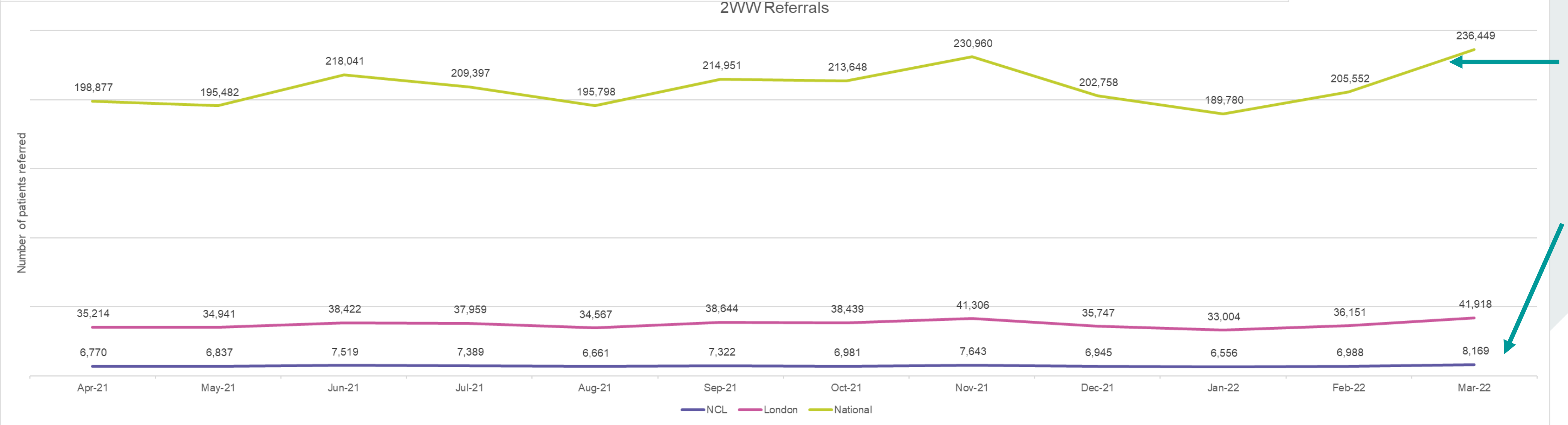
Transformation Partners in Health and Care

NHS

Cancer waits referrals and backlog



NCL 2WW referrals and 63+ day backlog, by month since April 2020.



Annual 2WW referrals:

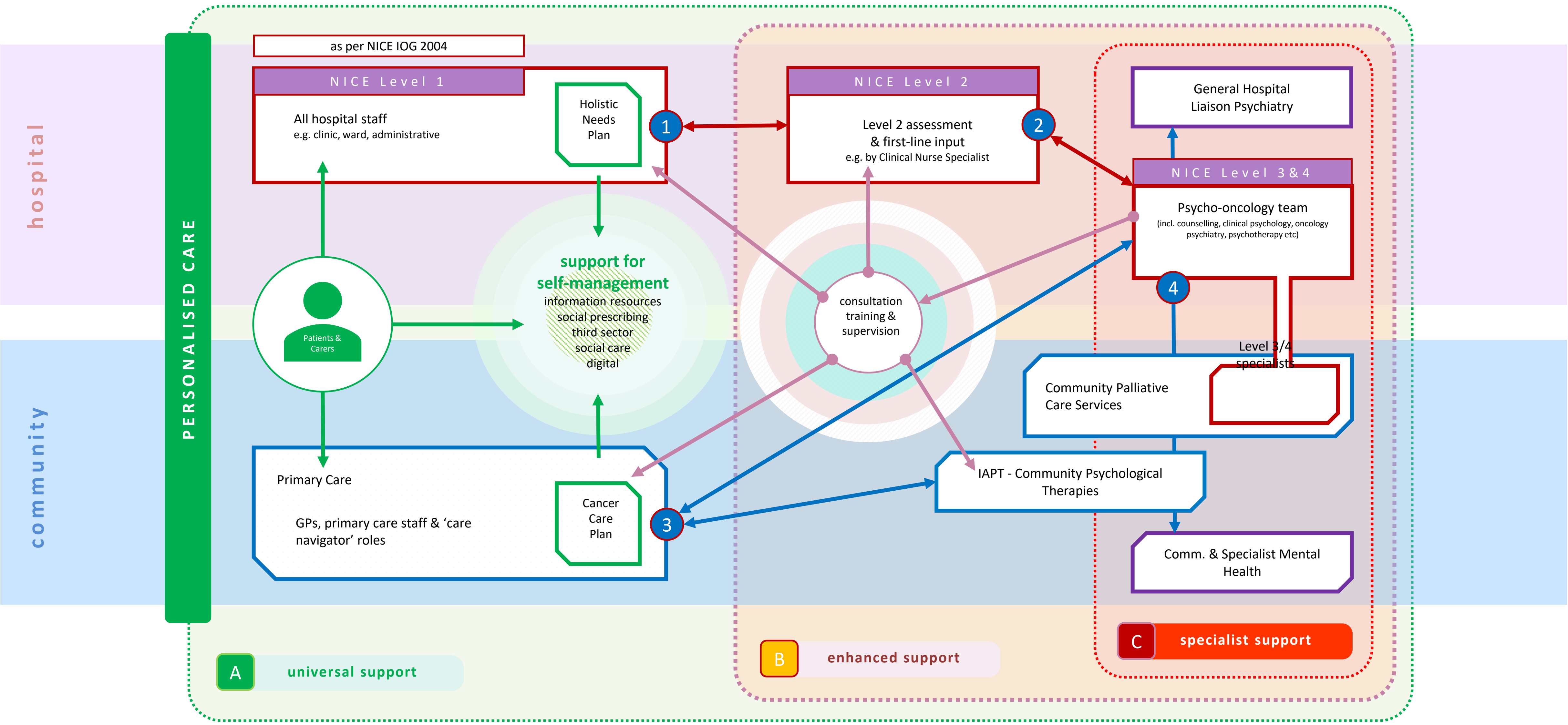
- National, approx. 2.5 million
- NCL, approx. 86,000

Improving cancer psychosocial support: the story so far

This project focuses on ‘psychological harm and distress’ on the cancer diagnostic pathway, both before a diagnosis has been made and before first treatment starts.

- Joint project in 2016, between TCST and London Mental Health Network, triggered a Macmillan grant for a pan London mental health clinical lead in TCST.
- TCST project, between 2017-2020, was preceded by regional project with London Clinical Networks about psychological impacts of physical health pathways (eg cancer, diabetes, stroke).
- Recognition across London that the psychosocial needs of those affected by cancer were not being adequately met, with confusion regarding when, how and where to refer.
- Clear evidence, confirmed by the mapping carried out in November 2017 that there was inequity in access to psycho-oncology services across London.
- Macmillan Cancer support funded a Pan London post to ensure that a pathway was developed to deliver excellent psychosocial support from diagnosis, through treatment, living with and beyond cancer and end of life care.
- The London Integrated Cancer Psychosocial pathway has been implemented within London and nationally. Macmillan have rolled out the “London model” across the four nations of the UK with significant financial investment.
- The National Cancer Team have used this work to underpin their National strategy for improving cancer psychosocial support which now includes psychosocial support as a priority area within the planning guidance for all Cancer alliances.
- The London pathway addresses psychological needs *from* diagnosis.

LONDON INTEGRATED PATHWAY FOR CANCER PSYCHOSOCIAL SUPPORT



hospital

community

PERSONALISED CARE

as per NICE IOG 2004

NICE Level 1

All hospital staff
e.g. clinic, ward, administrative

Holistic Needs Plan

1

NICE Level 2

Level 2 assessment
& first-line input
e.g. by Clinical Nurse Specialist

2

General Hospital Liaison Psychiatry

NICE Level 3 & 4

Psycho-oncology team
(incl. counselling, clinical psychology, oncology psychiatry, psychotherapy etc)

4

Patients & Carers

support for self-management
information resources
social prescribing
third sector
social care
digital

consultation
training &
supervision

Level 3/4 specialists

Community Palliative Care Services

IAPT - Community Psychological Therapies

Primary Care

GPs, primary care staff & 'care navigator' roles

Cancer Care Plan

3

Comm. & Specialist Mental Health

A universal support

B enhanced support

C specialist support

V5.6

Key features of the London integrated pathway for cancer psychosocial support

- **Integrated personalised care pathway** approach
- This is a whole pathway for psychological care from diagnosis, through treatment, cancer rehabilitation, recovery, living with and beyond cancer and end of life care.
- Key principles agreed based on widespread stakeholder engagement across London
- Distinction between **universal, enhanced** and **specialist** support
- Majority of people cope with support from family/friends, self-management, third sector, information and signposting. Preventing distress and promoting adjustment at the centre of the pathway
- Different services have key roles at different points along the pathway – no single service alone is sufficient.
- Pathway needs both Improving Access to Psychological Therapies Services (IAPT) and Psycho-oncology teams- **not either/or**.
- Psycho-oncology teams will **share expertise** across the whole pathway, including consultation and training with primary care and IAPT services.

2017-20 programme’s products were co-produced through extensive stakeholder engagement

- Commissioning guidance on Psychosocial support (published May 2018)- ***has had impact within and outside London***
- Mapping of cancer psychological services in London (November 2017)-***data has been used to inform commissioning decisions e.g across NWL and SWL STPs.***
- London Integrated Pathway for Cancer Psychosocial support-***has already been localised across several CCGs in London***
- Business case to support the implementation of the pathway and the development, where needed, of psycho-oncology services (published February 2020)
- Service specification for pathway implementation and the development of Psycho-oncology services (published February 2020)
- Refreshed Commissioning guidance for Cancer Psychosocial support (published February 2020)
- Refreshed Pan-London Mapping of Psycho-oncology services (February 2020)
- https://www.healthylondon.org/our-work/cancer/personalised-cancer-care/psychosocial-support-and-cancer/

Appendix B:

Focus group findings

Focus groups – sub themes (1)

1. **Reactions to the terminology of "psychological harm" and "distress"**
   1. "Harm" – unintended, long term, culpability, potentially irreversible
   2. **Distress" – expected, short term, personal resilience/tactics to manage**

   3.Impact on individual's function such as eating, sleeping, concentration, family relationships, engaging with healthcare appointments, denial

   4.Perception – impact of perceived delays versus actual delays, either way it can still cause harm.

   5.Irrespective of "harm" v "distress" - there are things we can do to minimise distress, promote adjustment and also provide different levels of support, depending on what individuals need (see system issues below).

2. Family dynamics during diagnostic phase

1. Previous experience of cancer and/or mental health problems, impact on family members/significant others
2. Patients not telling loved ones (to protect them)
3. Impact on the family
4. Impact that family dynamics can have on workforce capacity/resilience

Focus groups – sub themes (2)

3. System issues contributing to distress/harm

   a) Unreliable communications – cancelled appointments, not taking individual needs into account ahead of appointment setting, not being open/transparent, phone v face to face/video call (staff and patient experiences), inter-hospital referral processes. The importance of having a direct point of contact (key worker).

   b) Diagnostic pathway – by its nature, taking into account individual needs, managing expectations

   c) Impact on trusting relationships with healthcare professionals – primary care, diagnostic team, surgeons, oncologists, CNSs, impact on the entire patient pathway

   d) Impact on workforce of those system issues affecting patients – eg CSWs, CNSs, primary care e.g loss of control/helplessness, time.

4. Measuring/detecting harm and distress – acute care

   a) Predicting vulnerable groups who need proactive support – we have a very long list of suggestions!

   b) Flaws with psychological screening tools – thresholds too low, baseline measurements aren't currently captured (time consuming/additional pressure on overstretched workforce), multi-factorial causes (psychological wellbeing is relational), measuring psychological harm is far more complicated than measuring physical harm

   c) Develop a pathway for the most vulnerable

   d) Role of CNS, support workers, psycho-oncology, surgeons – there's a place for all of them to detect distress/harm, acknowledgement that workforce capacity is a major barrier to formal, contemporaneous assessments, value of level 2 comms training, access to supervision, need for good quality signposting/referrals

   e) Communications – improvement needed between (and within) primary and acute care teams, with patient

Focus groups – sub themes (3)

5. Measuring/detecting harm and distress – 2ww referrals

1. Clinician conversation with patient at time of referral – delays to getting a referral, any support networks?
2. 2ww forms – tick box for Severe Mental Illness (SMI) isn't sufficient, not used routinely either
3. 2ww Patient information leaflet – could be more explicit about what to expect, tips on how to manage, signposting if need extra support
4. Delays in notifying primary care of key information – diagnosis, primary care is rarely (if ever) notified by the acute care team when there is significant concern about a patient's psychological wellbeing
5. Role of primary care and community services in supporting people once distress/harm is identified – limited resource, appropriateness of cancer specific support when a diagnosis may not have been made yet, some generic support may be useful.

Focus groups – patients & carers

- Patients want honesty and openness - leads to trust
- re communications - reliability and accuracy leads to trust
- Uncertainty is distressing - let's be prepared for that
- Want the NHS to be proactive - signposting, referral and access to prehab services (once diagnosed and waiting for first treatment)
- Appointments - prefer to be in person, or video calls. Phone calls are not helpful.
- Family dynamics - impact of waiting for tests on carers, sometimes people choose not to tell the family straight away, secrets

Focus groups – primary care

- negative experience early on in the pathway (with primary care) can impact engagement on diagnostic and treatment pathways
- distress is time limited, harm is long lasting
- distress is inevitable, harm is preventable
- Formal harm review suggests culpability and need to say sorry
- we should be more proactive with vulnerable groups of people – re asking what support they have, how they will cope with dx pathway etc
- 2ww referrals – need to make sure we include SMI and also wider mental health history eg depression and anxiety. Also whether someone is isolated or vulnerable and will need support from 2nd care
- Need to be more proactive about asking how someone is and referral/signposting re practical and emotional support options – and this shouldn’t be hard to do. Assumptions made that patients don’t want to talk about cancer.
- Assessments – agree that there is lack of capacity in system whether primary care, cancer nursing, psycho-oncology or IAPT
- 2ww patient information leaflet needs to include information to normalise distress, tips to manage it and where to go if need further support.
- Primary care workforce – lack of awareness of what the diagnostic pathway entails, time frames and roles of MDT.
- Poor communication between primary and secondary care has significant impact on patient distress
- Primary care doesn’t find out about diagnosis until way down the line, so don’t expect to find out about any psychological red flags through diagnosis pathway.
- Often don’t complete the SMI tick box on referral form because have no idea what secondary care would do with that information anyway.

Interview - surgeon

- Harm – “an implication that someone/the system needs to be held to account.”
- Distress – “There are degrees of how someone is negatively impacted from a mental health perspective”.
- “I don’t think [psychological harm] is picked up very easily. Services are inundated with referrals. There is a lot of time pressure. It can be picked up by enquiring a bit more, usually by a CNS, once a patient is plugged into the cancer system. So as a surgeon, it isn’t well picked up at all through a physician assessment”.
- “We don’t stratify based on need, it’s a generic route in and people are seen generically. Although if someone has a hearing impairment for example we need to arrange things to help. Where we are in London, we may need translation services and usually scrambling at the last minute. The difficulties of taking a history from someone who doesn’t speak English for what is a complex subject matter? For someone who might also have mental health needs, it’s even more difficult”.
- “Pilot a service that is designed for those most vulnerable as you see it in the population group”.

Focus Groups - Cancer Nurse Specialists

- See themselves as best placed to identify psychological distress or harm on diagnostics pathway.
- Rely on body language, impact on daily function and patients not asking questions, to identify distress.
- Most didn't consider notifying primary care if someone is experiencing high levels of distress or harm.
- Struggled to give examples about their role in preventing distress and promoting adjustment before breaking bad news clinics.
- Challenges in supporting the family – before psycho-oncology would be involved and/or when no access to psycho-oncology for family members to access.
- some examples where CNS takes on emotional burden of the psychological impact of delays

- distress is inevitable when being tested for cancer
- primary care doesn't always tell patients that they're being referred for cancer tests.
- communications issues between primary care and acute care teams causes distress too
- managing uncertainty – delays in getting tests, getting test results, giving test results
- key workers are there to answer questions – eg breaking bad news, later on patient didn't understand things when diagnosis given or have new questions, sign posting

Focus Groups - Cancer Support Workers (overview)

- vast majority of CSW time is devoted to managing patient’s expectations and responding to their levels of distress/coping with uncertainty.
- you often lack of facts, don’t have the answers to questions, can’t tell patients the results even if you have them – all leads to uncertainty/distress
- normal for patients to feel anxious
- you provide tips on how to manage/signposting that anxiety, distress
- “it’s easy to contact us, but…” – time with patients and other impacts
- experience of phone v f2f/virtual – definite preference/feedback that phone calls are least favourite option
- you see the impact of primary care/referral on how the patient is and what you do/don’t know in advance
- it takes a lot of time to reverse mis-trust and/or scepticism in patients
- CSWs are the intermediary between patients and clinicians, less intimidating, ‘translators’, help patients prioritise questions and their needs
- family dynamics – such as supporting patients and carers, when patients don’t tell their family everything
- how you do/don’t use past history in interacting with patients

Focus Group – cancer support workers & their role in providing emotional support & containment

“For me personally, that psychological stuff definitely takes up more of my time than anything else, and more so at that early stage”.

“So I tend to talk a lot of people through how to manage their anxiety and so I'm talking to them, letting them know that that is anxiety that they're feeling and how to manage that. They might have some physical symptoms like tightness in their chest, they might be sweating and breathing problems things like that, but also trouble with sleeping. They're just not managing in themselves. It's very all consuming those thoughts and worries”

“Certainly from my experience as a support worker where we're easy to get through to, compared to the actual medical teams. And often I think the anger that's manifested from the stress and the frustrations of not knowing whether we can give test results over the phone, which obviously we can't even if we're on the system. So I think that adds to the frustration”.

“Although I might go into a conversation knowing a lot about a background about someone, I would treat them all the same. I feel it's nice to have it, but I do tend to keep it in the background when I'm communicating with them”.

“lots of my most distressed patients often come to me from the nurses. So I think always feeding back to [the nurses] is particularly important, especially when patients might not be ready to receive support or don't want help”.

I have had conversations, where patients have felt very angry and they blame their GP.

once you lose that trust a bit, to gain it back can take a long time, if you can at all anyway. Some patients just don't trust at all, and they just want to go private or they don't want to see a certain team. It can have really sad effects.

You feel that the person is now putting themselves into even more distress by isolating them from the very people that should be there to support them, not me, the family really. And I'm just a surrogate supporter. It's sad to see.

when it starts to affect the rest of the family dynamic relationship. Then I think that's when partners can be pushing more for them to be honest about exactly how they're feeling.

with one of the cases I hadn't read the notes beforehand. And then after, when I did, I thought ‘I wish I'd read that before’ because then I would have understood why he was saying those things to me. But to be honest, I will never forget the conversation that we had because it was really upsetting.

Focus groups - Support workers and access to supervision and support

“We have a psychologist. We've been having some support, with a lady who comes and supports us over online and she asked us how we are feeling and we talk about different scenarios to her and it's sort of sharing learning as well. And I've actually found it quite useful, but there are days that are harder than others.”

“I think there's always that worry that particularly if the person is in quite a bad way, that you haven't done enough or you could have done something better or different. I think you tend to doubt yourself as a professional in a lot in those in those situations. How you could have done things differently? But yeah, a lot of reassurance from the rest of the team and managers and things so that's really helpful and supervision as well”.

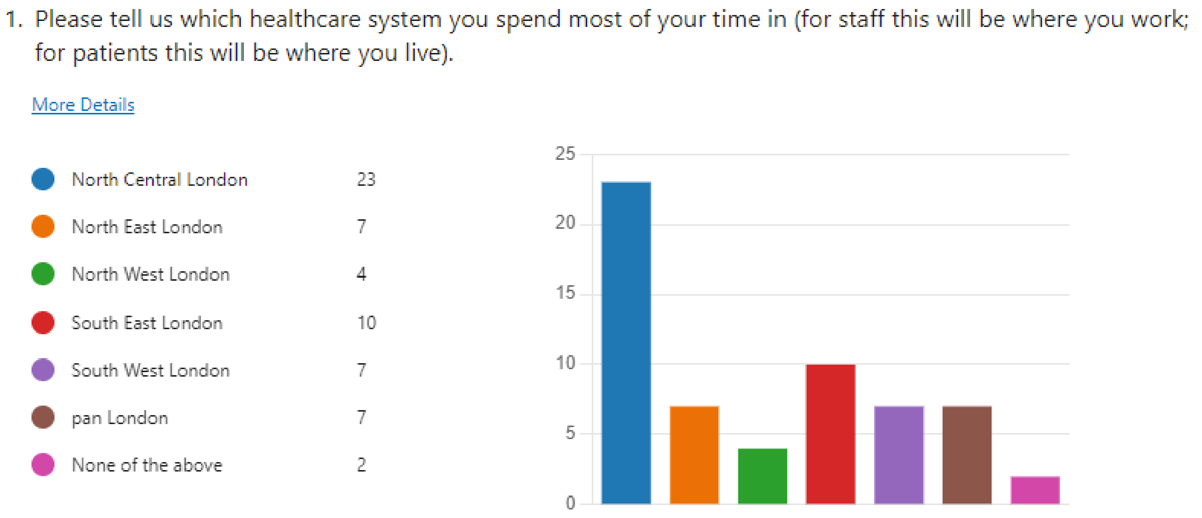
“We don't have that as something, it's only once every two months. So definitely colleagues makes things easier in the moment”.

Focus Group - Psycho-oncologists

- Relational impact of distress/harm on a person – family/carers, relationships with healthcare profs, family history of cancer/bereavements, other life events/experiences etc. doesn't fit a neat pathway. It means we need to be both flexible and systematic.
- Distress is normal, harm is not – blame & accountability re the latter. sliding scale between distress and harm.
- Flaws of measuring 'psych harm' – it's not like measuring physical harm, problems with the instruments ie low thresholds, difficulty in disentangling harm from perceived/actual delays, baseline measurement, difficulty in disentangling physical and psychological impacts (and why we don't want to do that). Complexity in unpicking the cause/s of distress. And is that helpful anyway?
- Can we predict who will need more support? - Eg those who are stigmatised, certain vulnerable groups, medically unexplained symptoms/MUO/CUP, who are "the people, if we had seen them earlier, we could have helped to facilitate work with the medical teams"?
- Communications – trust/reliability Importance of trust between NHS and patients/families – what takes trust away, once lost trust it's difficult to get back; clarity on what is known/not known, managing expectations, not using phones (video call/face to face preferred),
- Workforce – need sustainable options, no capacity in psych onc services & CNS, impact of messy system on both patients and workforce re holding distress, skill/expertise/training of others in asking about psychological distress/harm during diagnostic pathway
- Impact of COVID – on patients, families, workforce. Behaving like COVID hasn't happened.
- Be clear about what we do know and be clear about what we don't know.

Appendix C:
Survey results

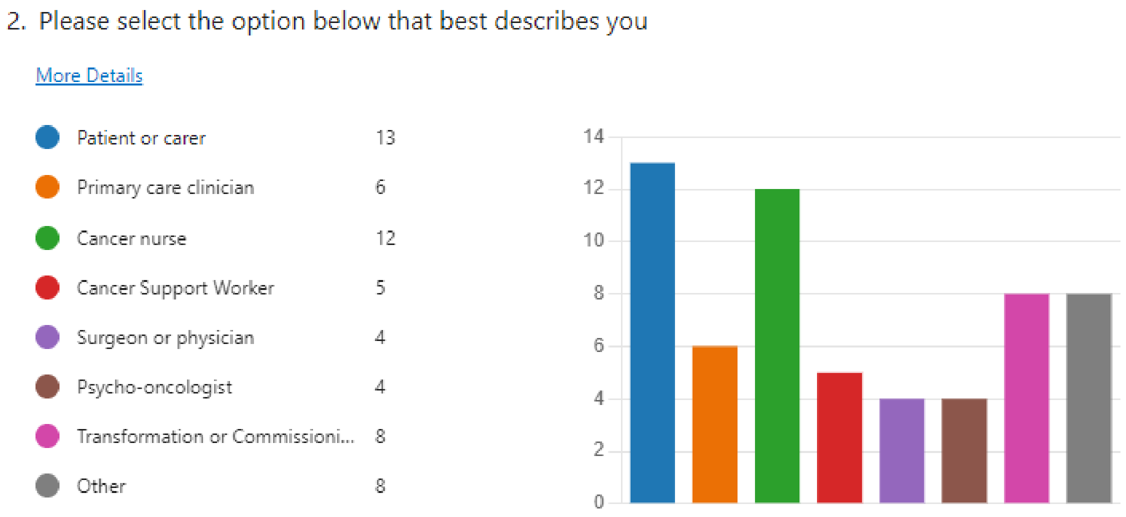
Survey respondents



1. Please tell us which healthcare system you spend most of your time in (for staff this will be where you work; for patients this will be where you live).

More Details

North Central London	23
North East London	7
North West London	4
South East London	10
South West London	7
pan London	7
None of the above	2



2. Please select the option below that best describes you

More Details

Patient or carer	13
Primary care clinician	6
Cancer nurse	12
Cancer Support Worker	5
Surgeon or physician	4
Psycho-oncologist	4
Transformation or Commissioni...	8
Other	8

Survey details:

- 31/1/23 - 12/2/23 (13 days)
- total 60 respondents
- Circulated to all of steering group members, focus groups participants and workshop delegates.
- Also circulated with a wide range of stakeholder groups, pan London and North Central London levels.
- 38% of responses came from NCL.
- 22% of responders were patients and/or carers.
- 20% of responders were cancer nurses.

From a patient partner

"Recognising psychological harm and working to reduce it needs to be as integral to cancer diagnosis, treatment and aftercare, in the same way that work to reduce physical harm is.

"At the moment the approach is patchy and, as a patient, it can feel like the ball is firmly in our court to both identify the support we need and to then find out how to access it. It can feel like a battle to get support at the precise time when having the emotional resilience to do this is at its lowest ebb.

"Having these principles not only gives those in healthcare the framework to deliver psychological support but also forms a commitment to the patient that the need for support is embedded in their cancer pathway."

Cancer Patient Partner, North Central London

Draft principles

1. **Every *conversation* counts** - balancing bite sized, manageable information along each step with clarity about what we do know AND what we don't know. This bite sized information has to be relevant to the person in front of the staff member. Primary care should use the word 'cancer' with the patient when they are making a 2ww referral – not using the word can cause greater distress later. We need to think beyond the patient and consider the needs of families too.

2. **Consistent, efficient and clear information builds trust and reduces distress** - Staff need to build relationships with patients and families to have complex conversations. Communication systems need to be reliable and timely between patients and all relevant NHS services. Information should be provided in different formats appropriate for individual patients and family members.

3. **Provide a named contact person on receipt of referral** – It is important that a professional keeps in touch with the patient to see how they are doing. This could be a navigator, CNS, or support worker.

4. **Make time to explore the emotional impact of the referral, diagnostics, and treatment process** - with patients from the very start. Let families know they can ask questions and have private conversations.

5. **Manage expectations by being clear about what we do know, and what we don't** – clarify what people understand about waiting; distress is normal when there is uncertainty; about the pathway itself (being clear on what is known and what is unknown at each point). It's important that we include families/significant others in how we support others with the emotional impact of cancer and managing expectations.

6. **At the time of booking appointments, proactively identify needs and arrange reasonable adjustments** – translation services, physical access, hearing & sight impairments, those with complex mental health needs etc. This includes sharing of information between primary and acute care teams, and mental health services and primary care/cancer team (where appropriate and with patient permission).

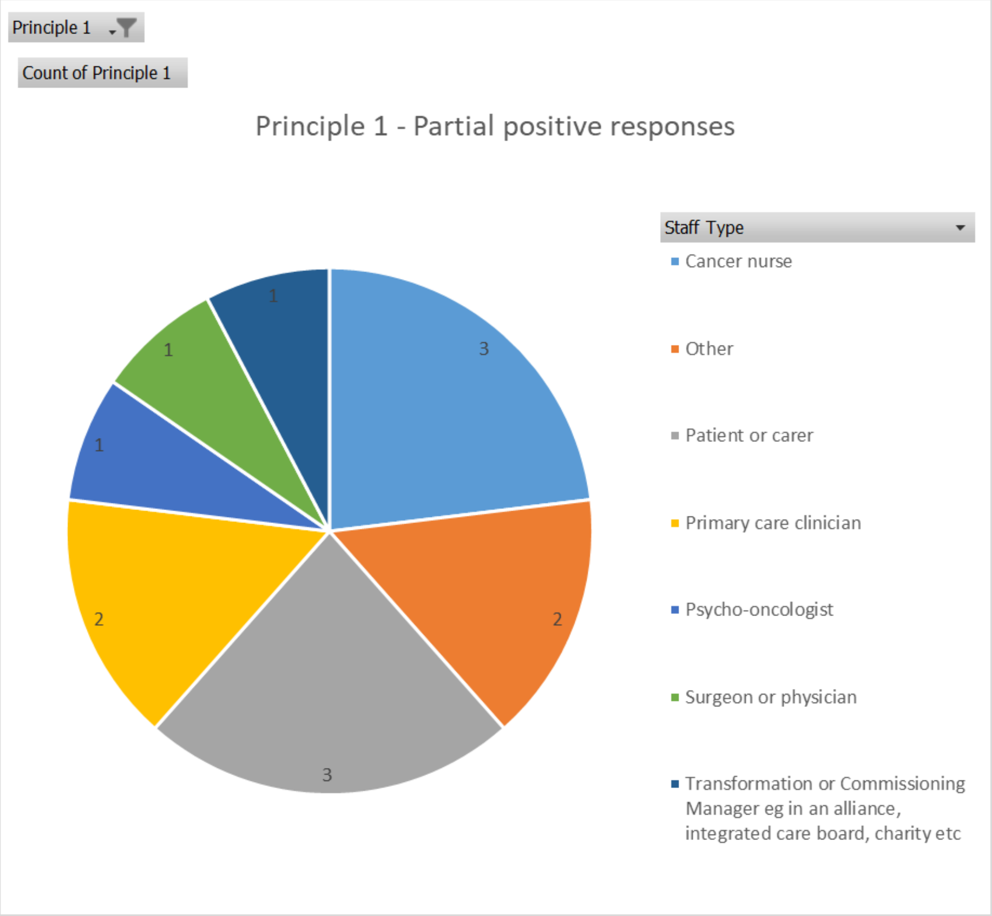
7. **Offer psychological interventions for families/partners too** - Most psycho-oncology services don't have funding or capacity to do this much needed work. Also need resources to offer bereavement/anticipatory grief support to family members. The offer tends to be inconsistent and ad hoc.

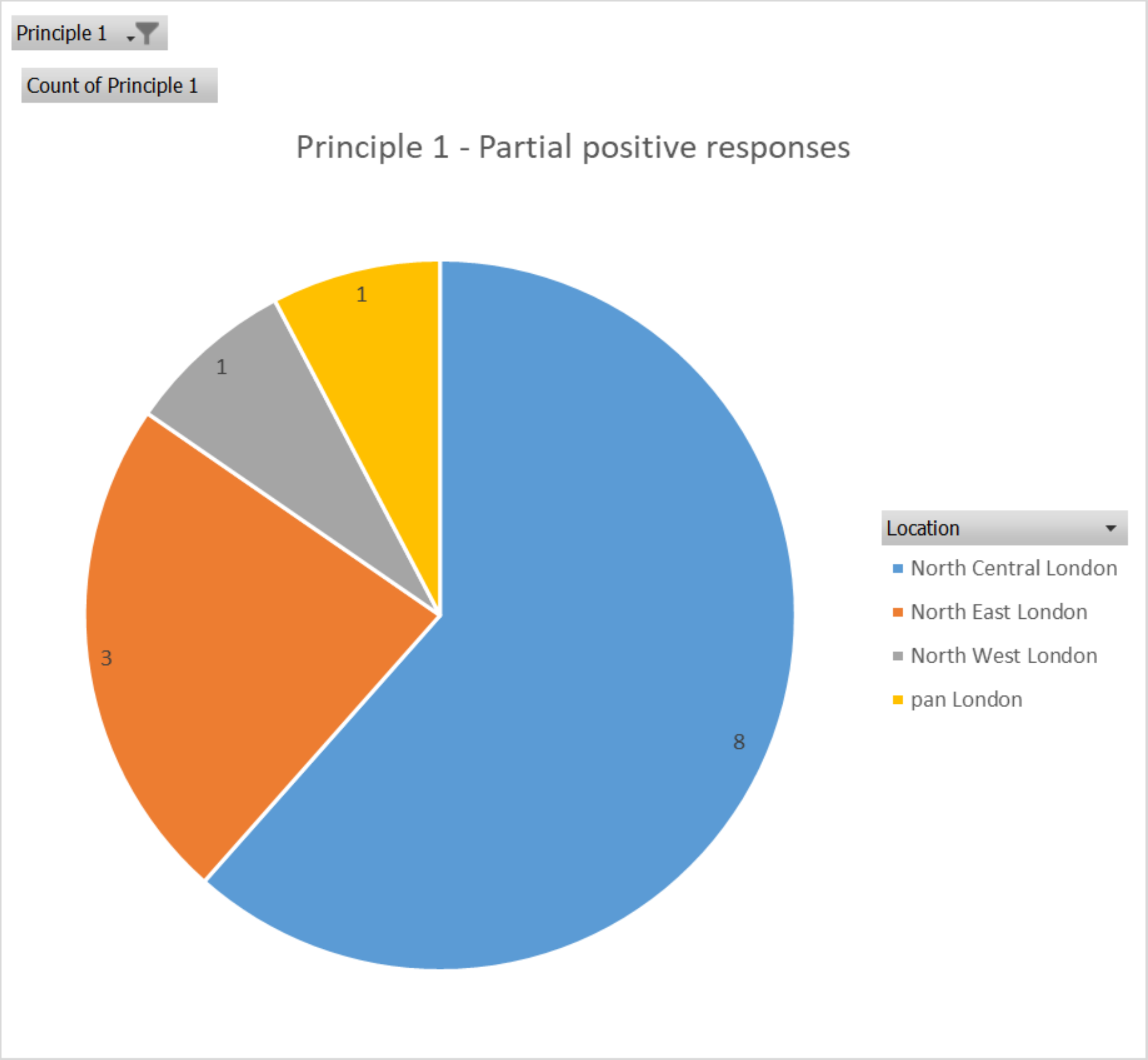
Response	P1	P2	P3	P4	P5	P6	P7
Agree	78%	95%	75%	80%	93%	95%	68%
Agree, partially	22%	5%	22%	20%	7%	5%	27%
Don't agree	-	-	3%	-	-	-	5%

“Yes, partially” responses to Principle 1

Principle 1: Every Conversation Counts

- Yes, definitely – 47
- Yes, partially – 13
- Not at all – 0

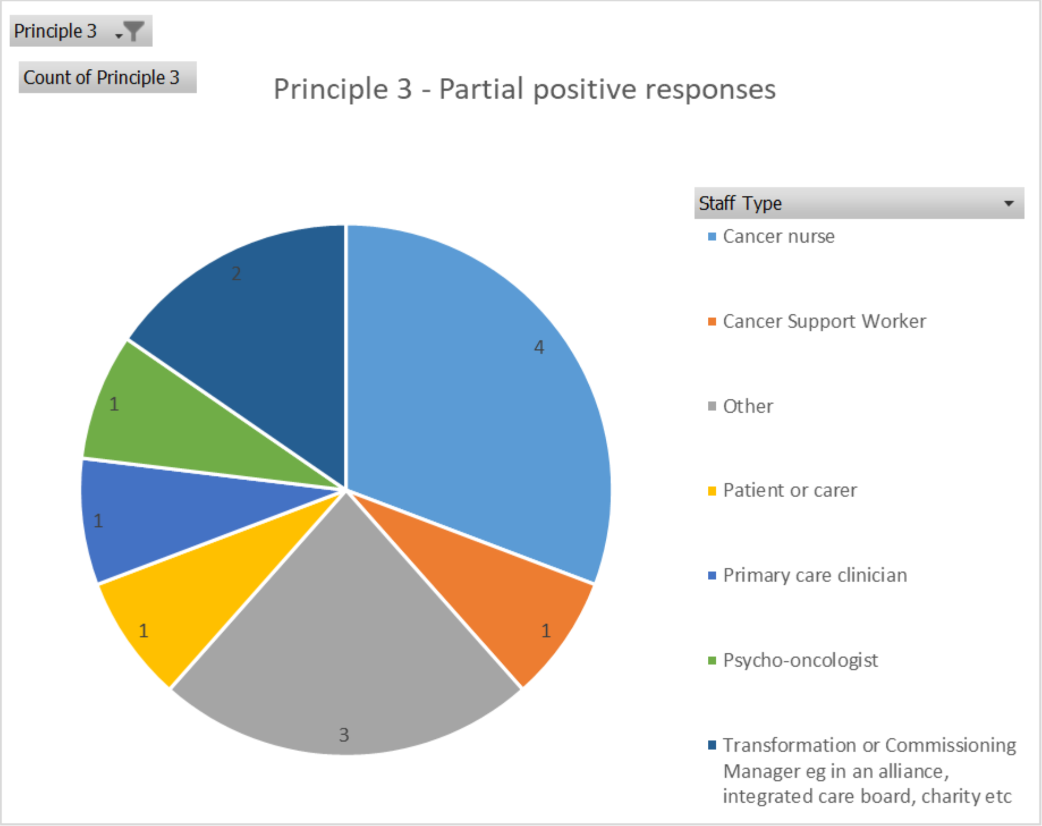


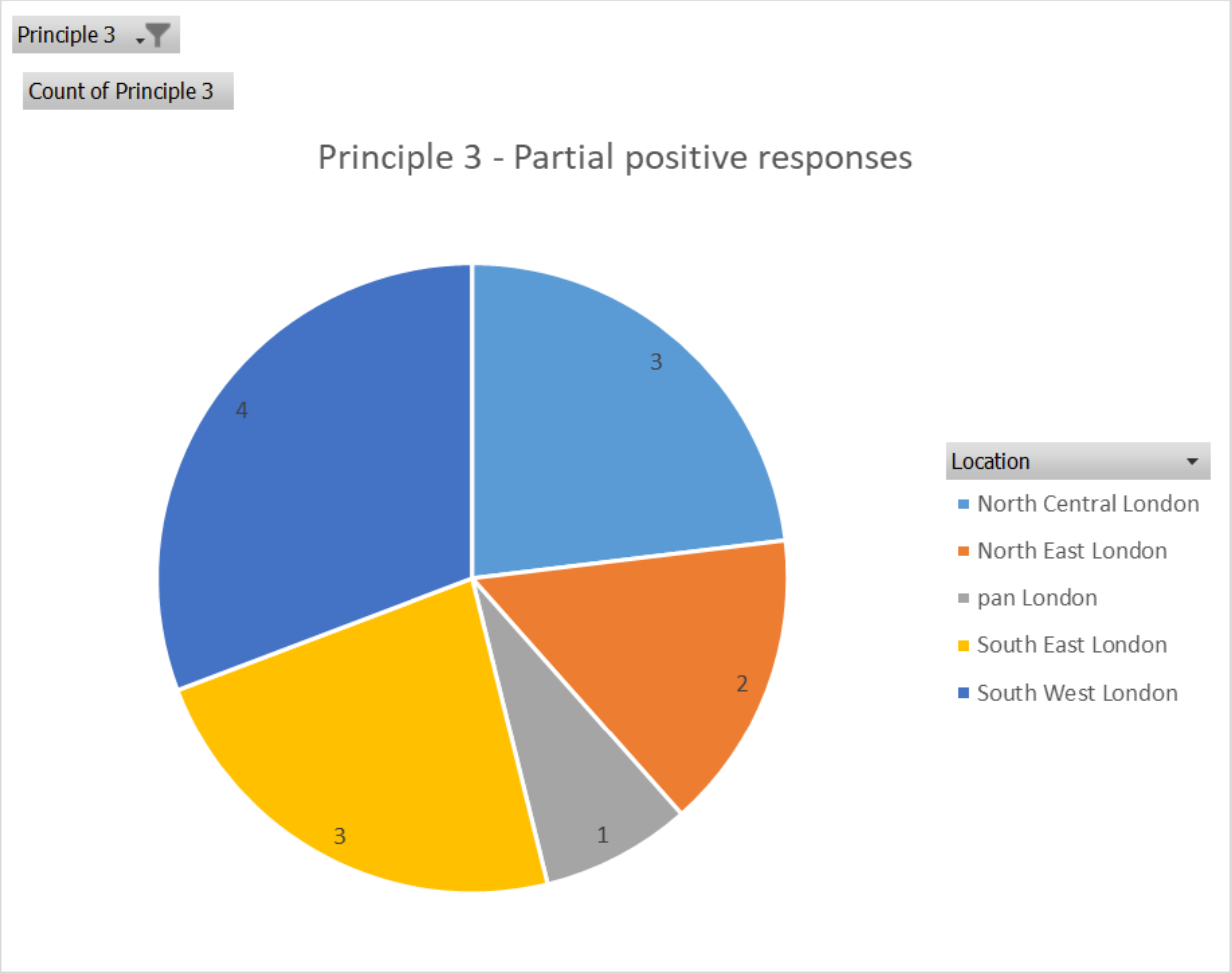


"Yes, partially" responses to principle 3

Principle 3: Provide a named contact person on receipt of referral

- Yes, definitely - 45
- Yes, partially - 13
- Not at all – 2 (1x SEL surgeon or physician, 1x SEL CNS)

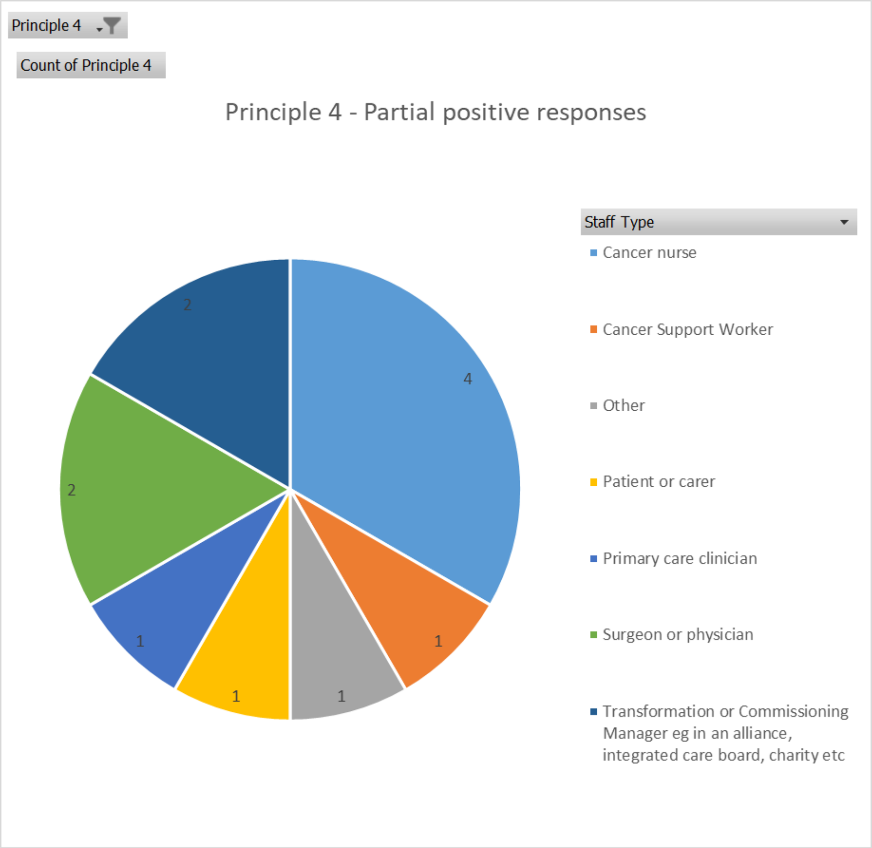


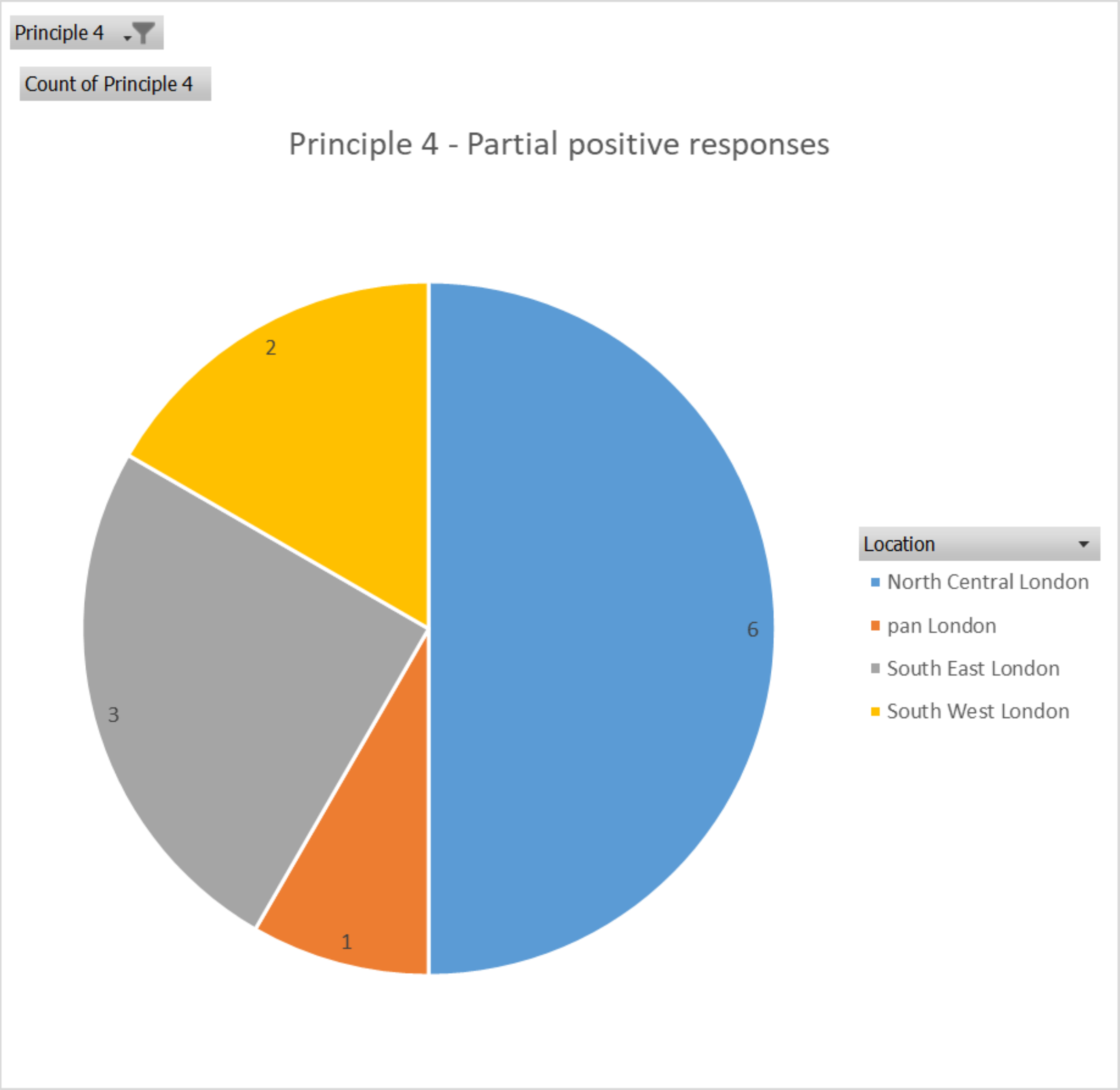


“Yes, partially” responses to principle 4

Principle 4: Make time to explore the emotional impact of the referral, diagnostics, and treatment process

- Yes, definitely – 47
- Yes, partially – 13
- Not at all – 0

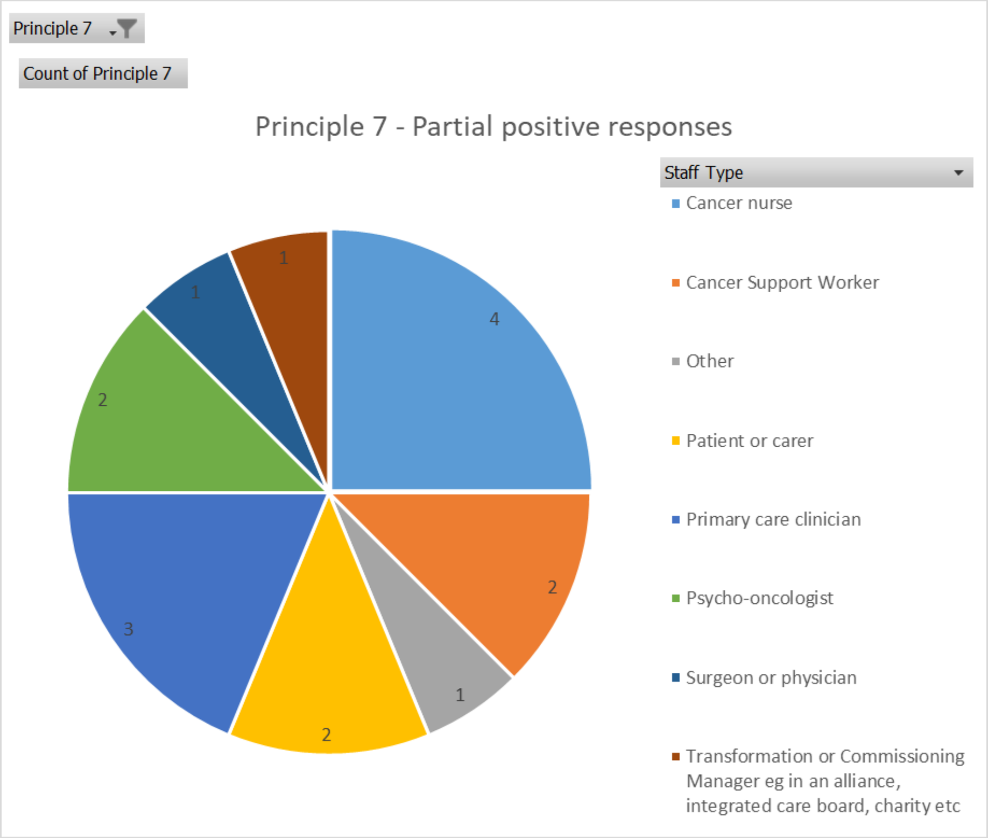


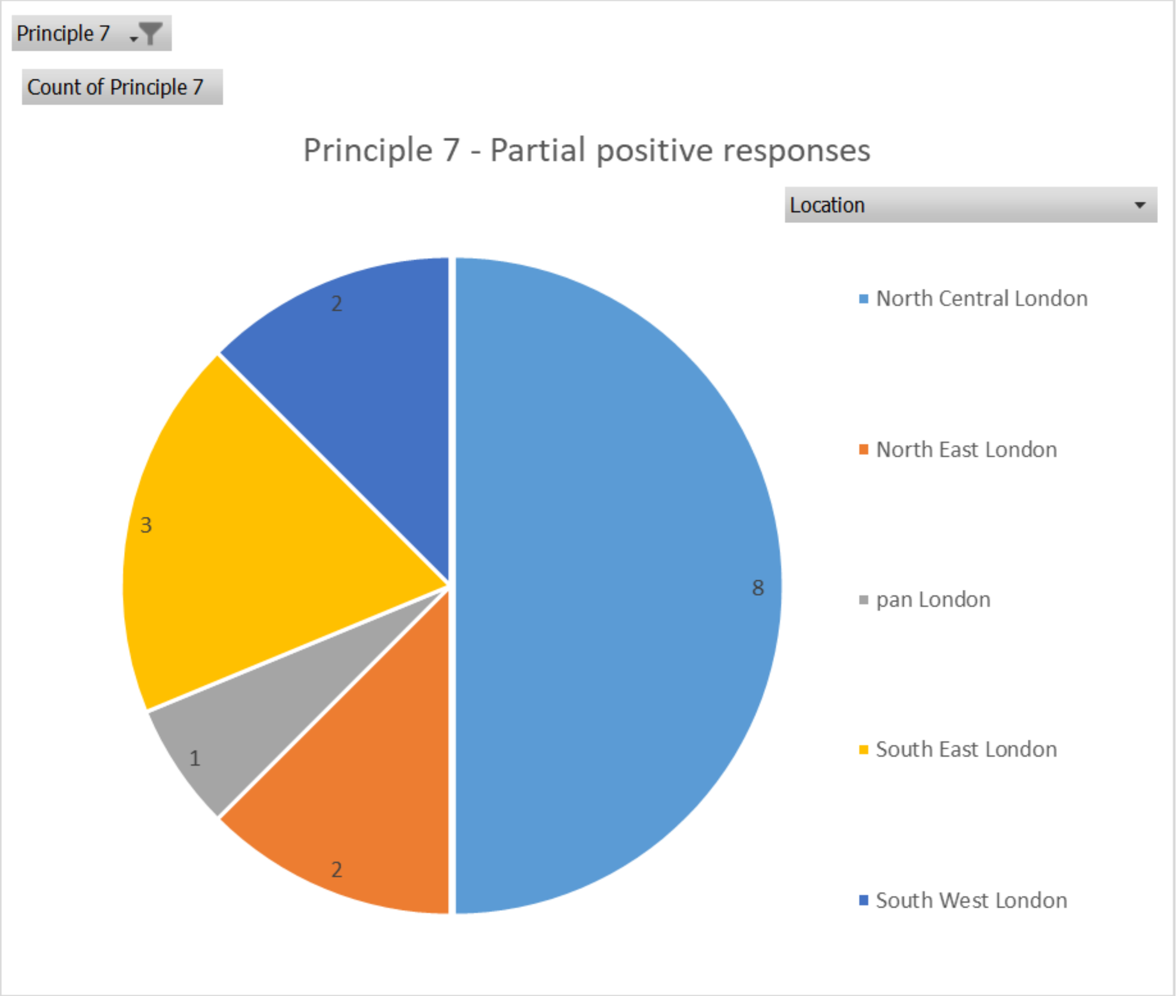


“Yes, partially” responses to principle 7

Principle 7: Offer psychological interventions for families/ partners too

- Yes, definitely - 41
- Yes, partially - 16
- Not at all – 3 (1x NCL CNS, 1x SEL surgeon or physician, 1x SWL Transformation/Commissioning/Third sector rep)

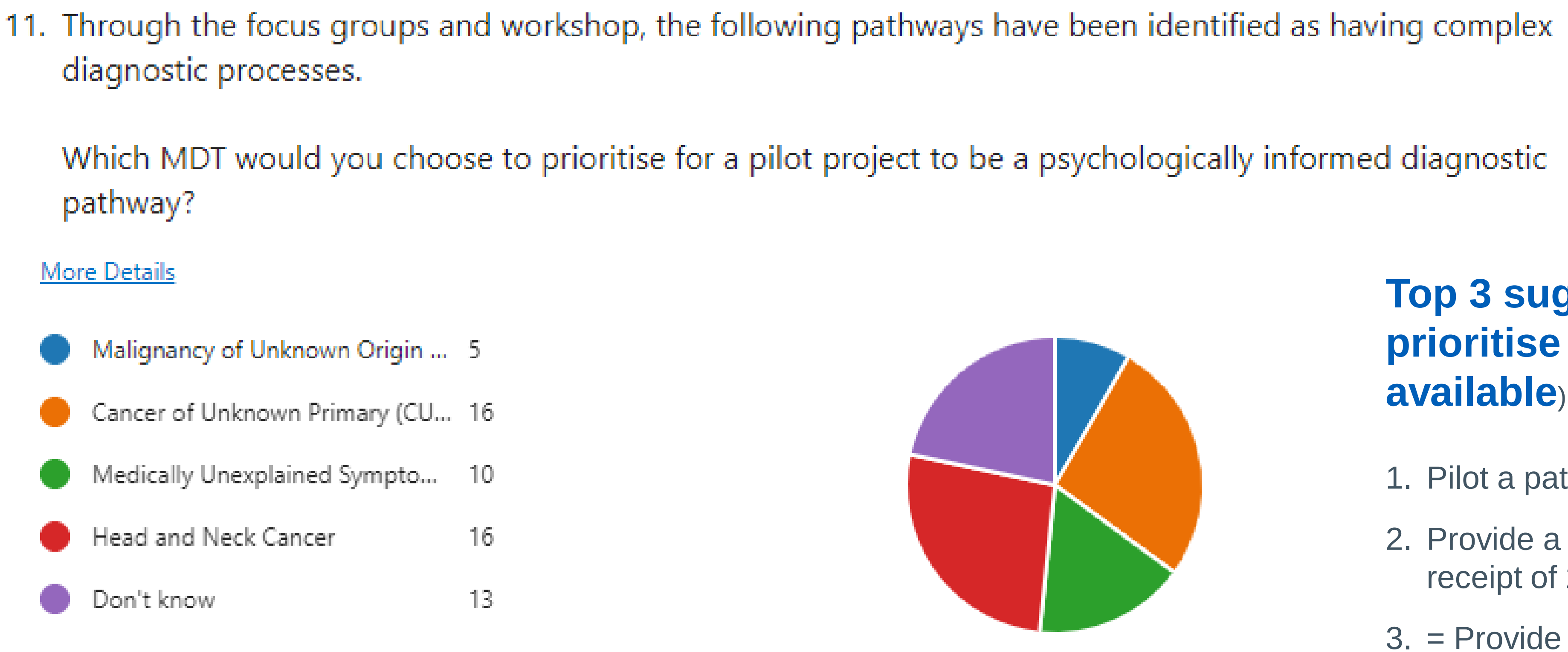




Further feedback about the principles

- A lot of feedback acknowledging that the principles are easy to agree with/gold standard. Much more difficult to apply pragmatically given workforce and time constraints within services "to deliver with resilience".
- Principle 1 - Be clear that using the word 'cancer' in referral conversations is on the premise to exclude cancer, given the <10% conversation rates.
- Principle 1 – include respecting when patients don't want to hear more and why bite size is necessary (to help people process info emotionally and cognitively)
- Principle 2 – needs to also be in different languages;
- Principle 3 - Named point of contact should be when there a high degree of suspicion is identified – ie do not wait for histopathology to introduce a key worker.
- Principle 3 - there should be a named contact for each patient and the contact name and details should be made explicit when given to the patient. The patient has the choice to engage at the level that suits them.
- Principle 4 – requires clarity on what constitutes private conversation with a family member (re patient confidentiality); include signposting to services.
- Principle 5 - include families/significant others in emotional support provision, if the individual consents to this; include signposting on where to find further support.
- Principle 7 – should not be limited to bereavement/ anticipatory grief; should include unpaid carers too; needs to be more aspirational. Offer needs to be explicit.
- Priority needs to be given to people with severe mental illness and those with complex needs
- Strategy needs to consider potential trainee roles for clinical discussions, eg CNS, psycho-oncology etc
- Important not to pathologize distressed reactions to diagnosis and treatment plans, People need time to cope.
- Principles should refer to shared decision making – a key component to effective personalised care.
- Principles must apply to all referrers in both primary and secondary care services
- Primary care needs bite sized information too from acute care, to ensure consistency with supporting patients. Includes knowing who the named point of contact is.
- Importance of audit/feedback mechanisms to see how the principles are applied and make any improvements as a result.

Prioritising an MDT to have a psychologically informed pathway



11. Through the focus groups and workshop, the following pathways have been identified as having complex diagnostic processes.

Which MDT would you choose to prioritise for a pilot project to be a psychologically informed diagnostic pathway?

More Details

●	Malignancy of Unknown Origin ...	5
●	Cancer of Unknown Primary (CU...	16
●	Medically Unexplained Sympto...	10
●	Head and Neck Cancer	16
●	Don't know	13

Top 3 suggested projects to prioritise (if funding was available)

1. Pilot a patient support line
2. Provide a named point of contact on receipt of 2ww referral
3. = Provide practical information about the diagnostic pathway
4. = Apply learning from St George’s Rapid Diagnostic Clinic model

Stakeholder groups re implementation

18. To deliver a selection of these ideas, a range of organisations will need to be involved. Please rank the order in in which you think organisations should be involved.

1 Transforming Cancer Services fo...
2 Cancer Alliances
3 Integrated Care Boards
4 Health Education England (Lond...
5 Charities

Acute trusts and primary care networks were described as being ‘automatically involved’.

Other suggested organisations/groups:

- SPIN GPs/GPNs
- Social prescribing
- Social media peer support groups
- Patient groups eg Healthwatch
- National Institute for Health Research
- NHS England Cancer Programme (keep informed)
- Unions (keep informed)

“My only concern about TCST leading the work is that ICB and Alliances will be the ones delivering it. There would be a risk that there is a mismatch between what could realistically be delivered.”

Prioritising the suggested actions (1)

Suggested project	Would require a lot of funding? (No/don't know)	Would take a lot of time to deliver ? (No/Don't know)	Already exists/ could be adapted? (Yes/Don't know)	How easy to deliver? (Easy, don't know)	Average score
Update pan London two week wait (2ww) patient information leaflet	93%	77%	95%	87%	88%
Provide practical information about the diagnostic pathway for families	92%	85%	75%	90%	86%
Develop standard process to send urgent emails to GP Practice monitored inbox of any psychological red flags	87%	72%	77%	65%	75%
Professionals working with patients need to use questioning techniques to build trusting relationships with patients.	82%	63%	78%	60%	71%
Standardise breaking bad news clinic processes	77%	72%	72%	55%	69%
Reduce/ remove using the telephone as a routine option for appointments with patients	77%	67%	67%	60%	68%
Provide good quality referral and signposting that meets the personalised needs of patients without overwhelming them	77%	60%	73%	58%	67%
Provide a named point of contact at time of booking a 2ww appointment	70%	65%	70%	63%	67%
Standardise 2ww process in primary care	78%	45%	90%	48%	65%
Standardise hospital 2ww processes	73%	48%	92%	45%	65%

Prioritising the suggested actions (2)

Suggested project	Would require a lot of funding? (No/don't know)	Would take a lot of time to deliver ? (No/Don't know)	Already exists/ could be adapted? (Yes/Don't know)	How easy to deliver? (Easy, don't know)	Average score
Standardise hospital 2ww clinic processes	67%	52%	82%	45%	62%
Apply learning from St George's Hospital's Rapid Diagnostic Clinic pathway and pilot in one MDT with a complex diagnostic pathway	62%	45%	68%	55%	58%
Joint safety netting project between primary & acute care teams	62%	43%	68%	40%	53%
Provide good quality Holistic Needs Assessments (clinical & practical needs section) and care plans before treatment starts	43%	32%	82%	40%	49%
Deliver an education package for primary care teams regarding psychological impacts during diagnostic pathway	45%	27%	77%	47%	49%
Implement pan London psychosocial pathway (TCST, 2020) from point of diagnosis onwards	40%	30%	73%	37%	45%
Deliver an education package for clinicians providing 2ww clinics about psychological impacts	40%	27%	67%	45%	45%
Provide a biopsychosocial assessment on entering the hospital's diagnostic pathway	48%	23%	58%	35%	41%
Pilot a patient support line during diagnostic pathway	32%	27%	55%	38%	38%
Pilot a "Carers School"	28%	32%	53%	37%	38%

Other feedback

“This is a great project with the potential to make real change in the future.”

“Well done on such a fantastic piece of work. Looking forward to outcomes of this.”

“pleased to see how this work is developing to help and support cancer patients/ carers.”

“We have to ensure we provide equal support to families with children as well as adults.”

“This questionnaire provides a good framework to think about all these issues; we need some plans and actions to implement the recommendations that result from it.”

“I think it has been the most interesting project I have been so far involved, a great sense, from all professionals, to move forward. I would really hope to get more involved and be able to help in a collaborative way through the work I am doing at present.”

“There is a great sense also we need to listen to patients' opinions, as professionals might sometimes overlook what really matters to them.”

“From a patient's point of view, what I can gather from my focus group, is the need to start with small, few changes that could make a big difference - more than think to make massive changes that could be very unsettling to process for patients too.”

Additional feedback from engagement meetings

- Recommend Level 1 Communications Training for Hospital 2ww access teams (one London Trust has done this successfully) and access to clinical supervision if needed
- Clarify roles & responsibilities for workforce on FDS pathway (eg support workers, outreach workers, Access office team, Registered Mental Health Nurses etc) that do not sit in the cancer team (as >90% of people will not be diagnosed with cancer), although they will need to work closely with the cancer team.
- Access to communications training (eg SAGE & THYME, “Level 1+”) and clinical supervision for support workers (eg via trainee psychologists)
- Is there further skills training needed for social prescribers?
- Consider the role of care coordinators (funded through Primary Care Networks) to support people to attend appointments.
- Priority groups – those with Severe Mental Illness, Learning Difficulties, DNAers and appointment delayers
- Patient portals – how well are they used, kept up to date with primary and acute care appointments (including the NHS app?) so that people have a ‘single source of truth’ about when/where their appointments are and for what purpose.
- Principle 3 – agree because “who do I contact if I don’t hear about results?” Develop a checklist/top tips for what this function encompasses. Could a “trainee CNS” role include this?
- Principle 6- Consider the role of volunteers (NHS Trusts, third sector) in providing assistance for people to get to appointments.
- “People before process”!
- Don’t let the ambition behind the principles get in the way of delivery, especially some quick wins.

Transformation
Partners
in Health and Care

For more information:

Liz Price, Senior Programme Manager (TCST)
Liz.Price4@nhs.net

https://www.transformationpartnersinhealthandcare.nhs.uk/our-work/cancer/