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Exploring psychological harm on the cancer diagnostics pathway

Summary of themes from focus groups

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Introduction

This paper sets out a summary of themes analysed as a result of 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 following groups of people:

- Patients and carers - who were diagnosed and/or treated since 2020.
- Cancer Support Workers (CSWs)
- Cancer Nurse Specialists (CNSs)
- Primary care clinicians – GPs and nurses
- Psycho-oncologists
- Surgeons/Oncologists.

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

This quote from a focus group participant is highly pertinent – How should we measure psychological harm and distress? Can we actually measure psychological harm and distress? What would the NHS do as a result of measuring it? What impact will that have for patients and their loved ones throughout their life course? These are the questions the project seeks to unpack and make sense of.

Following the focus groups, five overarching themes were identified:

1. Reactions to the terminology of "psychological harm" and "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

Sub themes have also been identified and these are described below, illustrated with quotations from focus group participants.

Please note that a small number of quotes mention experiences that may be triggering for others, for example anxiety, self harm and suicide.

1. Reactions to the terminology of “psychological harm” and “distress”

1.1 “Harm” – unintended, long term, culpability, potentially irreversible

“The psychological impact of waiting for cancer treatment is relative depending on how long you're waiting. And the longer you wait, the worse it gets, and especially if you don't know what's going on. I mean, I've waited a short time, and I've waited a long time, and both were uncomfortable because you don't know. Is the tumour growing? How quick is it growing? And the longer I wait, does it mean I'm going to more likely to die?”.

“What would be seen as very reasonable and a natural kind of uncertainty and … a pretty natural concern. Right the way through to much more extreme presentation, in terms of perhaps blurry, to much more mental health presentation and where a diagnostic label could be used”.

“Because harm’s got different levels. There's irreversible harm where the people are traumatized like PTSD [Post Traumatic Stress Disorder]. And then you’ve got harms, how long a patient has been waiting. But then surgery can go ahead and they can get through that. They are cured and in that way, the harm is only temporary”.

“Harm implies that something is actively done to another party and has an adverse outcome. There is an implication that someone/ the system needs to be held to account”.

“One patient a number of years ago, that was actually a ward patient who was given a diagnosis and started hitting herself when she got a diagnosis. That was more than a distressed reaction because she was harming herself. But that was her way of knowing that there was something wrong, and being stuck in a ward for a week whilst waiting for answers, and then come to a clinic and being told that”.

“One unintended consequence could be around litigation. So at the moment you can't really sue if there's been no harm. So in order to have a successful litigation, a patient has to prove that harm has come. And at the moment I don’t think the psychological harm, because it's not measured, it's not diagnosed it, it's very difficult to prove”.

1.2 “Distress” – expected, short term, personal resilience/tactics to manage

“I think for me it's about anxiety. I'm coming in to assist where patients, in breast for example, they come in finding a lump from the GP. They had their necessary investigations on the same day. They have a biopsy on the same day, but then they have a period of waiting. And I think it's that waiting that causes a lot of anxiety, uncertainty, lots of thought processes go through patients’ heads. We might suggest to them that we are worried and this could be suspicious of cancer.”

“Distress talks about the negativity of impact, but perhaps it’s not as an emotive word. Harm is implying that there has been an adverse outcome. There are degrees of how someone is negatively impacted from a mental health perspective”.

“I think until you have that certainty of a diagnosis, your brain just goes mad doesn't it, researching what could it be”.

"I'm convinced there is harm but how do we measure that and how do we put it into a methodical way? That that we can then take to other people, to Commissioners, to hospitals and secondary care and say this is the measurable harm that's happened".

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

"A lot of the feedback I get from patients is that it's the longest week of their lives, they haven't been able to concentrate, they haven't been able to work. It has a huge impact on their mental health during that investigative process".

"I think a lot of patients get really stressed out thinking that it's just them".

"It could be a 'how are you feeling?' questionnaire. And you give it repeatedly as you move through the pathway".

"If they're in denial and they stop engaging and they're in the middle of the diagnostics and they've got full capacity, what do you do?".

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

"Are we saying well this is a delay, this is waiting or is that about people's perception of there being a delay? Because it might be well within our targets of what that is, but for that person that might feel like a really long time. So I guess that's a subjective experience of a delay as well, and how that's captured in that definition."

"If your diagnosis is one that is amenable to treatment and you haven't been diagnosed ultimately until a later stage, which you could argue that the course of the cancer has not been affected, you might still have suffered a lot of distress. But as you work through that pathway and people explain the effects of the preciseness of the diagnosis and all that comes with it, then that distress may dissipate and you may not have harm. Or you might have harm. It depends".

1.5 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).

"So maybe it is all about resilience. Maybe we should turn this so it's about what's required to make people feel resilient? I could imagine asking patients and getting some really interesting answers about what makes somebody feel resilient along a pathway that's extended".

"It's all a very uncertain time period, and we don't know when the information will come and what it all means".

“Sometimes I reflect and wonder whether we're using the right language and whether some of the language we choose is likely to or could risk prolonging the experience for the person concerned”.

“So they might not be able to get support from some of the national charities because they're not yet a cancer patient, but some of it is generic, isn't it?... whether the system that would make this really work would be something special, wouldn't it? To be able to draw together the different sorts of third sector support that do exist”.

2. Family dynamics during diagnostic phase

1.1 Previous experience of cancer and/or mental health problems, impact on family members/significant others

“In my experience, a lot of people when they come they already have baggage. Especially people with a history of anxiety, depression or unable to cope in general, day-to-day life. The people who had their relationship broken down or financial difficulties and all that”.

“We had a patient who came to oncology one day and because he knew. He said ‘I know that every time you walk in a room before I go in, I know that bad news is going to happen’. And that patient decided to take all their tablets there and then, in front of the doctor”.

1.2 Patients not telling loved ones (to protect them)

“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, it's almost as though it's some kind of process that they go through. And some people take longer and some people take shorter time. But there's a definite phase where they've got the information and other people might not have it yet and they're hanging on to that for a little bit and that time is quite interesting until they do tell the relatives”.

“He said, ‘I didn't want to tell her everything, not because I have a bad relationship with her, but because I'm just trying to protect her’ ”.

“It's the patient’s wishes that we have to respect. They’re our patient, but actually you just made me remember a really young chap with kidney cancer. We didn't even know he had a wife until he until he died and his wife went through his papers and then made an appointment with us, to see us and ask us why we didn't tell her. And ohh my goodness that was so tricky”.

1.3 Impact on the family

“With your question around who can identify the harm, and I was just thinking when you guys were talking about that, actually sometimes the partners and other caregivers are probably sometimes the first to identify it. I think initially in that first two weeks that they can be a lot of denial, and not really identifying in themselves that they may be struggling. But the partners and other loved ones can see it, and so sometimes it might come from them.”

“I get a lot of patients and sometimes the patient says ‘I'm coping OK, but actually it's my partner who's very anxious’. You see a lot of time it’s the husband who is diagnosed with the cancer. His wife will be lobbying for him. I want his appointment to be expedited. I want him to be seen quickly. I want the operation to be done very quickly. And sometimes it could be, vice versa like wife has got a cancer and husband is lobbying, or the children are lobbying for that on behalf of their parents, especially when people have comorbidities and they have to wait for prehabilitation”.

“When I give them the holistic needs assessment and the partner’s there on the phone saying, ‘I you know they said they had no concerns, but no we sat down together and actually there was then a whole list of concerns’. That’s when the patient realizes, which can take a lot of time, that the thought of being a burden and then realizing actually these people are here to support you. I think often people don't like seeing the family or friends upset. Or don't want to give them any of the burden of having to look after them. They're often a lot more open then, particularly when pushed by other halves, so I think it's really when they can start to open up”.

“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”.

“Distress describes an emotion and therefore it might be more likely to be transferable to other people who are in close a close relationship, those that live within the same context as the patient? So relatives, spouses, children.”

1.4 Impact that family dynamics can have on workforce capacity/resilience

“Because they can't have surgery and they have to be under observation rather than subjecting to the heart surgery or oncological treatment. So then we get a lot of calls from the patient’s family, who wants them to have treatment and want us to have another thought or have another assessment”.

“Sometimes a husband who will say “oh, look, I'm fine. It's just my wife. She can't cope. Do you have any support for her”? And so I’m sorry our services don't support the family. But if she's got an ongoing issue, she needs to go to the GP and seek some psychological support for herself. So we don't have that kind of support where we can support the families as well. We don't have resources and time”.

“So when I worked in surgery, there were different sort of levels of distress that you would see. When I worked in oncology, seeing patients’ distress going through treatment. In surgery, for example you wouldn't accept someone shouting at you. You wouldn't accept someone swearing at you. In oncology, I do a bit more because I can completely understand how frightening it is and how distressing and upsetting it is”.

“Sometimes you can get families who don't give the actual patient an opportunity to voice their concerns, they talk for the patient. It’s managing that when you are in the clinic room breaking bad news, it's managing in a case by case basis. Putting the patient at the centre of what their needs are”.

“Sometimes you're very grateful to the assistance that families give with translating, if the patient doesn't speak English. But I have got this one situation at the moment where I have a son and he’s making all the decisions for his father. And he doesn't want further investigations, but we're not able to speak to the father because the only contact details we have is the son’s. And he's saying no to diagnostics”.

3. System issues contributing to distress/harm

1.1 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).

“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”.

“How long am I likely to wait? If they are unable to say when will it be, that basic communication, but I think it's stuff that's done quite poorly actually. Just so you’re held. I think you're right, be clear about what you can tell people and be clear where you're uncertain”.

“When I'm talking to patients on the phone, the phone definitely is a barrier”.

“I was actually chatting to a gentleman recently who it was his wife with the brain tumour. And she actually physically couldn't manage to get to the hospital to have the results and actually just having that option of having a video call meant the world to her because she unfortunately was struggling with incontinence. To get there just wouldn't have been possible for her, so having that option again versus the phone it. It just meant so much being able to see the consultant and then they can see her as well”.

“I think the most important thing is that they’ve got that point of contact, that they don't have to go through Switchboard to be able to contact you if needed. That they've got a clear line of communication to you if needed”.

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

“They don't understand that they come in and we can't do a same day scan, same day biopsy. Some might be shocked that they have a blood test today, then they'll get a phone call for a scan, then they'll get a phone call for a different type of scan. Then they'll get a phone call for another scan, then biopsy. Then they’re understanding that the time that it takes for Histology. Then trying to process why then they need to wait for an MDT [Multi-Disciplinary Team meeting] and then they get their bad news. So it's a huge journey and with a lot of hurdles and a lot of different emotions on that journey”.

“Even if it is a cancer and patients know that there is a plan, there is some relief and then it's focusing on the next step of that journey, whether it be CT or MRI and giving appropriate time scales and results really as soon as possible. We only have two weekly MDTs. It might be waiting two weeks for answers which is a long time when you're the patient”.

“When I was having a pet scan. And I said I was anxious to the person I just saw. Yeah, well, I'm anxious. So they wanted to move me because one of the machines had broken and wanted

to move me to Harley Street. And I said I was too anxious to be moved. And at the end, the regular person doing the scan said 'Are you feeling less anxious now?'. And actually I thought 'where do I begin?'. Because actually what you really want to know is what it showed, the scan."

"A patient recently said to me, he ended up howling because he found it so claustrophobic even though he had asked for someone to talk to him. That's how he described it. Yeah, they had to stop."

"Some of the tumour groups that deliver, like liver, will basically have their MDT maybe twice a week because they're quite busy and we get the feedback, for example, quite easily. I've got one lady at this moment. She came in through bowel cancer screening and then she was told that she's got mets, which was found in a polyp. Then we in reach to the next MDT and the overnight MDT might only be once a month. So there's been a delay with receiving the slides. So that person has been told by the way, you've got a met. She doesn't know what's a met. Of course everybody googles at this moment. Actually no one said back to her, there's a delay. This is when this comes to happen. And for her, I felt so bad because it was horrible. She was just told, 'yes, we found the cancer'. That's all she can remember the word cancer. She doesn't know the type we were talking about. I just felt so bad because two weeks later nobody has spoken to her. Because she came in under another umbrella, she didn't come under our system. She goes in with another hospital, which basically doesn't review the cases as often as others, because they are not as busy as other centres."

"Difficulty in swallowing, as a symptom, touches on many different areas of speciality -ENT [Ear, Nose & Throat], Head and Neck surgeons, cancer, upper gastroenterology, neurology, Speech and Language Therapists. Patients often present through the Emergency Department (ED) with complications of swallowing, eg chest infections. At a time of COVID risk, the symptoms are similar to covid eg shortness of breath, wheezing, can become compromised eg aspiration leading to pneumonia. If they come through the ED, they come into Intensive Care Unit with long stay and complex needs, and with complex discharge arrangement needs".

"Even if the results are there, having to wait for the appointment, even if I'm on my computer I can see what the diagnosis might be. That inability to share with them. When you're waiting for that, you think it happens overnight, but actually it does take quite a long time to get the full diagnosis so that the accurate information can be given. And I think in amongst the stress as a patient, you're not necessarily thinking of that, you just want to know a diagnosis. And it's not always as straightforward as that".

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

"I've also had patients that have gone in with questions. But they haven't understood the answers because they say that the medical teams are talking way above them, and they feel too embarrassed to stop them. And then I have to reassure them that it's OK to say 'I'm really sorry please. I don't understand what you're saying, can you explain it to me in my terms and references'. They do feel frustrated by it and I think that can cause a barrier there and mistrust as well".

“When they are in robot mode, I call it robot mode because it's not engaging the patient, just kind of reading the answer. So they know why I've been booked into see them but they haven't communicated what I'm coming to the hospital for. That or an e-mail would have helped with that. So when I come in and they're about to start, and say ‘oh you're taking blood thinners’. ‘Yes’. ‘Oh, we can't do the procedure’. ‘I've been waiting for three hours’. These are basic things and it just shows me that they're not really engaged with me. So when that happened, and it happened twice and for me twice was too much... that's such a big deal when the little things aren't going well for me, it means it doesn't fill me with trust that the big things will go great”.

*“Their scepticism about healthcare in general and not trusting, not wanting to comply with treatments, not wanting to go to appointments. The kind of ‘if it takes *now* to get to the hospital’ thing. ‘Oh, what's the point’. ‘Now he's going to listen to me anyway’ kind of thing. Maybe it takes one person to actually sit there with them for a longer time than the 15 minute appointment, to sit with them for 20 minutes. It takes a lot to reverse those thoughts”.*

“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”.

“If we're talking about going forward with stratified follow up and these very patients who have lost trust lost and confidence in the system. And then they're being asked to trust that they can be discharged back to primary care with no fixed follow up that they already struggled to get in the first place”.

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

“I’m only a support worker”.

“For me personally [as a support worker] that psychological stuff definitely takes up more of my time than anything else, and more so as well at that early stage”.

“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”.

4. Measuring/detecting harm and distress – acute care

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

“we can usually see who's likely to be more at risk because they are coming from adverse backgrounds, that they haven't got a network that can support them there. There's the dysfunction with it, the poverty, all of the things which usually exclude people or mean that that the potential for their concerns to be picked up and kind of follow through are lessened. So we can usually pick those folk up.”

1.2 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

“It's also about what screening things you use, because if you use things like a PHQ 9 and the GAD 7 [two mental health screening tools], you're going to get tons of people who just get ‘I’m really stressed!’. It's so unhelpful.”

“How do you separate out what is distressed, because you're in the cancer pathway, to distress that's caused by a delay or a wait? Because if you've got no baseline, how do you know what's additional distress because of the wait? And I think that separating out, defining, measuring all of these bits is messy.”

“It's like everything, who's looking at the results? The CNSs are already struggling to do their holistic needs assessments. You would hope that this would feed into the psychological part of that holistic needs assessment. But I would only ask the questions if I was going to do something with the outcome. So it’s chicken and egg, we identify that there's a problem. But is there a solution? Do we put the solution in place, anticipating there's a problem? Or is there already an existing service?”.

“I would be very worried about creating an awareness with descriptive language where you become the victim. Because when you make patients victims, they become disempowered and we should not disempower them”.

1.3 Develop a pathway for the most vulnerable

“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?”

1.4 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

[The person who would do a psychological assessment] “needs to be someone who has time set aside and the experience of being able to capture that information, know where the support might come from and how to tap into that. For me day to day, my immediate go to people are cancer CNSs but they’re very limited in their time”.

“Often the diagnostic time is the worst time because they know there's a problem, but they don't know what the answers are and what the plan is. I think the key worker and nurse specialist being that support during that time, is imperative to the patient experience. Flagging up patients that there might be concern with the consultant and their GP”.

“The onward support needs to allow individuals to get what they need, it’s signposting and referral. But it needs to be someone who is aware of pathway difficulties, the needs of patients and problems in the system”.

“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”.

“Often the doctors and the consultants pick up on it but don't have the time to explore it, so then then they’re referred to us. But the conversation can't necessarily happen at that moment because of the time pressure”.

“Try and assess the level of distress or harm, make it like a proper assessment. I’d make sure that there's really clear documentation in the patient's notes saying about distress and making sure that that is part of it. It's not just about scan results and MDT outcomes. Actually documenting how the person is coping with the story so far, the diagnosis so far. I'd make sure the team knows. And for us, if we refer on to other teams for treatment to make sure there's a good handover. I'll make sure the MDT knows as well. So when they're making clinical decisions about treatment, management and maybe prognosis, that they [the MDT] know how they're [the patient] affected by news and information. It's very important that that's clear”.

1.5 Communications – improvement needed between (and within) primary and acute care teams, with patients

“So if a patient goes to their GP with water work problems, the GP may be thinking prostate cancer, but refers to a two week wait urology clinic. At no time has cancer been mentioned and routinely they'll come to our clinic and they won't know that the cancer word is a possible diagnosis. And the other side of it is, proactive patients may Google who we are, what we do. And that may be the first evidence that the GP's thinking of cancer when they see oncology clinic”.

“It's about the way that information is communicated. It might be that they’re asking me [the GP] to do something. So it might be, ‘I spoke to this patient on the phone today. I got so far, but I'd really appreciate it if you would follow them up’. Brilliant and perfectly happy to do that. But I'll use the analogy in antenatal care when they first started screening for depression. Then we just started getting these random template letters with the name filled in and a tick. This patient has been identified as having mental health issues. Over to you. And then you'd look in the notes. And yes, I know they've got a long history of depression. Are you asking me to do something? Are you just letting me know? So sometimes just getting a letter is not helpful at all”.

“The biggest side that I see is while people are waiting for an appointment. I think we don't always know. We do the referral. We don't always hear in between, unless there's a problem. And so it's mainly if something's gone wrong and that calling reception or there's lots of stress or they can be administration problems that it could be a problem”.

“There can be a loss of trust and a loss of confidence in primary care and you can see that in a measurable form just looking at the patient satisfaction survey where that question in ‘how do you feel you were supported in primary care?’ ”.

“It's important that we [the hospital team] know if there's a patient that's got some psychiatric issue”.

“We don’t stratify based on need, it’s a generic route in and people are seen generically. Although if someone has 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. And when it’s covid too… when we didn’t have the ability to allow others into the room, when patient has been told to come into the hospital but can’t bring someone with them”.

“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 because it's the beginning of my relationship with the patient. I don't want to have too much from the past influence. The person that they are now, they might be a very different person. So it's nice to know and I'd bear it in mind, but I don't agonize over it too much. I know it's there, but now this is the start of a new relationship. I'm starting with this person. I want to be as professional and as open and available to them as possible”.

“I would expect somebody to put a note on the system as well so that everyone can read it because when we make our calls, I think it's important that we're aware. It will just help us to deal with things a little bit better and prepare ourselves”.

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

1.1 Clinician conversation with patient at time of referral – delays to getting a referral, any support networks?

“Maybe [other GPs] always ask what support [the patients] have. I don't ask that when I do a referral, unless it was a patient that was very elderly or I knew was vulnerable. This conversation is making me think. I probably never think ‘ohh. I wonder, I know this patient has had a history of anxiety. I wonder if this is going to bring all that back’.”

“I've had a few conversations with patients where they felt that they weren't listened to initially by their GP and you know it was almost nearly a misdiagnosis and if it hadn't been for the patient or a loved one in the family pushing that, then yeah, that could have been a total misdiagnosis. And then that it gets to a point that when it is diagnosed, that it's too late almost and that they've got metastases. And it's not really curable, but I have had conversations, where patients have felt very angry. And they blame their GP”.

“I think there's a lot of work we could do around what patients are told at that first presentation or conversation with their GP, about what to expect and what the diagnostics entail. And although it's a suspected cancer pathway, it's also obviously to rule out cancer as well”.

“There's a lot of people that wouldn't want the extra help or wouldn't feel they need it. There's lots of people who when you refer them, they're not that worried about it. Whether that changes over time or once they leave the surgery, when things perhaps sink in it might be different”.

1.2 2ww forms – tick box for Severe Mental Illness (SMI) isn’t sufficient, not used routinely either

“Specifically thinking about psychological impact, perhaps the things you've just talked about. So if somebody has any history of a mental health illness, not necessarily just what might be considered an SMI, because I think most GPs wouldn't consider depression and anxiety that we diagnose and manage, an SMI. So I don't think it would occur to us to put that in an SMI box.”

“It’s always useful to know where the baseline is, when someone is coming into a stressful scenario like whether someone might have cancer or not. Good to know things, for example obvious mental health needs, social needs. Although I recognise that primary care is very busy and there are lots of obstacles in their world.”

1.3 2ww Patient information leaflet – could be more explicit about what to expect, tips on how to manage, signposting if need extra support

“I think probably flagging [on the 2ww patient information leaflet] that some level of psychological distress is normal for people going through the cancer pathway where we know it can be worrying, et cetera. It's good to talk to loved ones about this if you'd find that helpful. And if not, and talking to somebody would be helpful, these are your options. Just something pretty high level but explicit.”

1.4 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

“We [primary care] don't find out when they're cancer diagnosed. So my expectations of finding out about psychological distress is very low unless it's been given to somebody who has capacity to do it. And I'm not here to bash secondary care. They've had a really tough time. But this issue existed long before COVID. I don't find out at the end of their treatment that they finished their treatment. I didn't get the PSA value at which to refer them back in on stratified follow up”.

“We [the hospital team] send a notification and then, a phone call just to make sure it's been received. A cancer notification, so the GP is aware and then I know they get a clinic letter. But that that might be a couple of weeks afterwards by the time it gets through a system”.

“I think as a GP, I might just want a heads up for want of a better for phrase. You know, ‘we've identified this patient, their distress levels are a bit higher than we normally see on a cancer pathway. We're a bit worried about the risk of this is. Could you reach out to them? Could you ask one of your other team members to reach out to them?’.”

1.5 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

“We are behoven as a system to be prepared to be resourced to provide the solution, otherwise I think we will have done more harm. So how do we move to that position, so that we don't do more harm?”.

“What we're really talking about for a lot of people is practical support as well as you know someone to chat to. Not necessarily CBT or psychoanalysis, but rather where can I get a grant? How can I sort out my parking permit and what do I do about sickness certificate and getting those little bits and bobs sorted that is actually often psychologically alleviating for my patients”.

“[Social prescribers] are a good source. They have time… They're listening and helping, almost like a care navigator and I suppose unblocking the patient from progressing”.

“If we're talking about somebody who's unable to move forward, getting deeply distressed then it probably does need to be a psychologist, whether IAPT would?”.

“Coming to see your GP for a chat can be really useful but that won't be a standardised thing. That will be dependent on relationships, depending on trust, dependent on whether or not they felt supported initially. And so that can be variable”.

“I could imagine we might easily need to dip into the resources of charities like Mind to help, and they'll come straight back to us and say, ‘gosh, we're really strapped’.”

“Our boroughs are very different, and even within the boroughs, you've got the deprived areas and you've got the more affluent areas. What we don't want to be doing is pushing those resources into areas where they've already got plentiful resources. We want to be finding those silent populations. Really we want to be finding those ones where actually we're not reaching out successfully to them”.

Next steps

A half day workshop is being held on 30th November 2022 in central London. All those who expressed interest in the focus groups, steering group members and wider stakeholders were invited to the event.

The workshop will explore psychological harm on the cancer diagnostics pathway. The objectives of the workshop are to:

- Share the themes that have come up through the focus groups with patients & carers, cancer support workers, cancer CNSs, primary care clinicians, psycho-oncologists and cancer surgeons and oncologists.
- Share headlines from the literature about psychological distress/harm during diagnostic pathways.
- Work together to make meaning from these learnings and identify next steps.