

FOI – 202300342230 – document 1

From: REDACTED@gov.scot>
Sent: Tuesday, 05 July 2022 15:01
To: REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @gov.scot>; REDACTED @gov.scot>; Lorraine Simpson <REDACTED@thelinesbetween.co.uk>; REDACTED @thelinesbetween.co.uk>
Subject: RE: SG Pain Panel

Great – will send Teams invite.

Thanks
REDACTED

REDACTED
Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

From: REDACTED @thelinesbetween.co.uk>
Sent: 05 July 2022 14:56
To: REDACTED @gov.scot>
Cc: REDACTED @gov.scot>; REDACTED @gov.scot>; Lorraine Simpson REDACTED@thelinesbetween.co.uk>; REDACTED @thelinesbetween.co.uk>
Subject: Re: SG Pain Panel

Hi REDACTED

Thanks for getting in touch. We're delighted to have won the contract and look forward to working with you and the team. For your information, I've sent a signed copy of the contract back to REDACTED in procurement today.

Could we try 2pm tomorrow? As you say REDACTED is on leave and I am holding the fort, but I've asked REDACTED as Deputy PM, if she could sit in - between us we can hopefully answer any initial questions. I'm checking everyone's availability, but it currently looks like next Tuesday afternoon or Thursday are good options for the inception meeting.

[OUT OF SCOPE]

Thanks,
REDACTED

REDACTED | Research Manager
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: REDACTED
www.thelinesbetween.co.uk | @thelinesbetwee

On Tue, Jul 5, 2022 at 11:37 AM <REDACTED@gov.scot> wrote:

Dear REDACTED

I'm from the policy team in Scottish Government who have commissioned the Pain Management Panel. Following on from awarding TLB the contract for this work I was wondering if we could arrange a short call this week to discuss some of the details and arrange the inception meeting. Aware that REDACTED is currently on leave so will just be an informal check-in at this stage to align diaries etc.

I have good availability for a call today after 2pm or anytime tomorrow.

Thanks
REDACTED

REDACTED
Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

FOI – 202300342230 – document 2

From: REDACTED@gov.scot>
Sent: Wednesday, 06 July 2022 14:45
To: REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @gov.scot>; REDACTED ; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk; Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Subject: Chronic Pain Resources

Hi REDACTED

Lovely to meet you and REDACTED today, looking forward to working with you and the team on the Pain Panel.

Ahead of the Inception meeting next week, see some resources below that will hopefully provide further context for this project. As discussed on the call, it's important that we can demonstrate the Panel is a fairly good reflection of the diversity of experience of chronic pain across Scotland, including seldom heard voices.

1) Draft Framework for Pain Management Service Delivery: [Framework for Pain Management Service Delivery \(Draft for consultation\) \(www.gov.scot\)](#)

- **What is chronic pain** – see p6, 7 for some high-level information on pain, its impact and inequalities
- **Stats/Evidence base** – see p.37-38 for most of the data we have gathered on pain and its impact

2) NHS England survey data on chronic pain: [Chronic pain in adults 2017: Health Survey for England \(publishing.service.gov.uk\)](#)

- **Evidence base** - This is the best quality data on pain impact on society in any of the UK nations at present.

- We are replicating this in Scotland in our 2022 Scottish Health Survey, but results won't be available until Sep 23 at the earliest.
- Therefore we should use this as a baseline to inform recruitment to the Panel – bearing in mind other Scotland-specific challenges (e.g. remote, rural, Highlands, Islands etc)

Hope this is useful, if you want to discuss anything please let me know.

Thanks

REDACTED

FOI 202300342230 – document 3

From: REDACTED@gov.scot>

Sent: Wednesday, 13 July 2022 18:39

To: REDACTED@thelinesbetween.co.uk>

Cc: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>; louise.mcinnis2@gov.scot>

Subject: RE: Chronic Pain Resources

Hi REDACTED

Confidential materials attached – not for sharing widely

Thanks for you and colleagues' time yesterday. I'm on leave from tomorrow to 24 so please copy in my colleagues Cc'd to any correspondence going forward.

I said we'd share some materials so please find these attached. Please treat all of these as confidential please and do not distribute more widely than necessary.

1) **Scottish Health Survey Questions** – worth reviewing these to see how they're screening for chronic pain . **FOI see document 3a**

2) **Presentation from yesterday**. The infographics are lifted from this report on the English Survey data: <https://www.versusarthritis.org/media/23739/chronic-pain-report-june2021.pdf>

3) **Analysis report of consultation on Pain Framework**: This is to be published later this month alongside the Implementation Plan. Helps demonstrate the range of views on chronic pain but also did a good job of reporting on these in a measured way. . **FOI This is available on the SG website – exemption Section 25(1)**

4) **Framework Implementation Plan**: Sets out 18 Actions that we will seek to deliver in order to improve care and services for people with chronic pain. This will be published later this month and will be the main document to use with the Pain Panel in terms of gathering their views on priorities and approaches to

implementation of the Actions/ outcomes. **FOI This is available on the SG website – exemption Section 25(1)**

If you need anything else **REDACTED** or **REDACTED** will be able to help.

Thanks
REDACTED

REDACTED Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

From: **REDACTED**
Sent: 07 July 2022 11:26
To: **REDACTED** @thelinesbetween.co.uk>
Subject: RE: Chronic Pain Resources

Hi **REDACTED**

Attendees from SG below:

REDACTED
louise.mcinnis2@gov.scot

Thanks
REDACTED

REDACTED Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

FOI 202300342230 – document 3a

Chronic Pain

ASK ALL (0+)

[AnyPain]

Are you currently troubled by pain or discomfort, either all the time or on and off?

- 1 Yes
- 2 No

IF AnyPain=YES

[More3m]

Have you had this pain or discomfort for more than 3 months?

- 1 Yes
- 2 No

{IF'Yes'AT More3m}

SitePain

Where is this pain or discomfort?

CODE ALL THAT APPLY

PROBE: Where else?

- 1 Back pain
- 2 Neck or shoulder pain
- 3 Headache, facial or dental pain
- 4 Stomach ache or abdominal pain
- 5 Pain in your arms, hands, hips, legs or feet
- 6 Chest pain
- 7 Other pain

IF More3m=YES

[ImPain]

Over the past 3 months, how often did your pain limit your life or work activities?

INTERVIEWER READ OUT

- 1 A lot
- 3 A little
- 2 Not at all

IF More3m=YES

[SeenP]

Have you used any of the support or people on this card to get help or advice to manage your pain?

SHOW CARD C2

CODE ALL THAT APPLY

- 1 NHS or charity information about managing pain including online resources
- 2 Your GP
- 3 Nurse or other health worker at GP surgery/Health centre
- 4 Physiotherapist
- 5 Chemist or pharmacist
- 6 Specialist pain services at a hospital such as a doctor, nurse or physiotherapist
- 7 Residential pain service where you have stayed away from home
- 8 Psychologist
- 9 Osteopath, chiropractor or acupuncturist
- 10 Homeopath or other alternative medicine professional
- 11 Other – please specify- GO TO OPEN RESPONSE
- 1 None of these

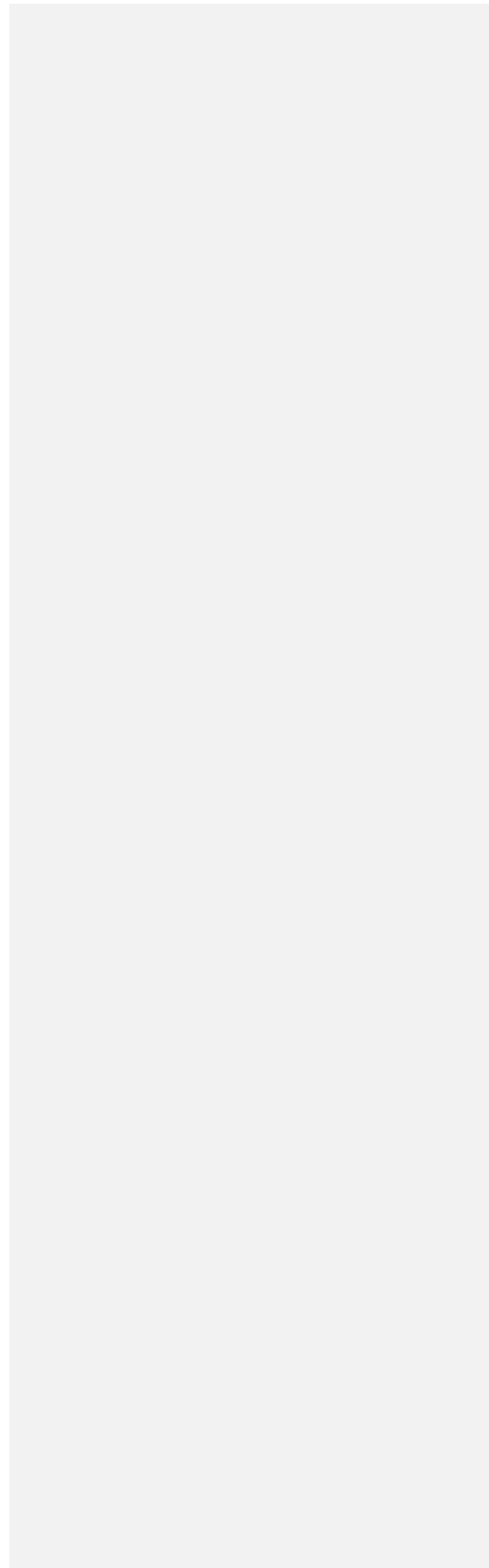
IF SeenP=Other

[SeenPx]

OPEN RESPONSE: Can you please describe who or what type of support you used?_____



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- document 3b PDF.p



FOI - 202300342230 – document 4

From: <REDACTED@thelinesbetween.co.uk>
Sent: Friday, 15 July 2022 14:27
To: REDACTED @gov.scot>
Cc: REDACTED @thelinesbetween.co.uk>; REDACTED@gov.scot>; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk>; REDACTED; REDACTED @gmail.com>; REDACTED @gov.scot>; louise.mcinnis2@gov.scot>
Subject: Weekly progress update

Hi REDACTED

Great to meet you on Tuesday. As promised, here is our first weekly email update.

In addition to updates by email, we discussed making arrangements for weekly calls, given the fast moving pace of this project.

I propose to send the weekly update email by noon each Thursday, and schedule a call by Teams for 4.30 the same day. That should give you time to read the email before we talk - at the catch-up, I can provide further detail and answer any questions (we can also cancel the meeting if you feel it is unnecessary).

If you agree with that structure, let me know and I'll send you a calendar invitation to the Teams meeting. The exception is next week when I'll be on annual leave - REDACTED will send you the weekly progress update, and if you need a call we can do that in the week of my return (w/c 25th July).

In summary, **the project is ON SCHEDULE**

This week we:

- Reviewed the background documents you shared with our team
- Attended the inception meeting

Next week we will:

- Send you the inception report
- Submit our first invoice
- Develop and submit a sampling framework

Actions for SG:

- I'd be grateful if you could arrange for a PO to be issued; we need the PO number for our invoice.
- Please send the materials you referenced in the inception meeting when they are available (consultation analysis, implementation framework, etc.).

I hope this update format is helpful - don't hesitate to let me know if you have any questions.

Best wishes
Lorraine

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From: REDACTED@thelinesbetween.co.uk>
Sent: Monday, 18 July 2022 16:38
To: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>; louise.mcinnis2@gov.scot>
Cc: Lorraine Simpson REDACTED@thelinesbetween.co.uk>; REDACTED@thelinesbetween.co.uk>; REDACTED@gmail.com>
Subject: Pain Management Lived Experience Panel - Inception report

Good afternoon everyone,

As agreed at the inception meeting last week, I have put together a short inception report summarising our discussion.

I hope this meets your expectations. As set out in the last section of the report, next steps involve us designing a sampling framework and screening tools. We hope to have these with you by the end of the week.

Please let me know if you have any feedback on the report or require any additional information.

Best wishes,

REDACTED

REDACTED Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: **REDACTED**
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Scottish Government Pain Management Lived Experience Panel Inception Meeting Report July 2022

Introduction

Scottish Government Chronic Pain Team (SG) and The Lines Between (TLB) met on 12 July 2022 to discuss the Pain Management Lived Experience Panel project that SG has commissioned TLB to carry out. This report summarises the discussion at that meeting.

Attendees

TLB

- Lorraine Simpson (role: Project Manager, providing regular updates to the SG, overseeing recruitment of the panel, supporting at workshops, quality assuring the data)

analysis and the production of the draft and final report).

- **REDACTED** (role: recruitment, supporting at workshops, analysis and report writing).
- **REDACTED** (role: recruitment, leading workshops, analysis and report writing).

SG Chronic Pain Team

- Louise McInnes
- **REDACTED**
- **REDACTED**
- **REDACTED**

Apologies

- **REDACTED**, TLB (role: recruitment, supporting at workshops, analysis and report writing)
- **REDACTED** (SG)
- **REDACTED** (SG)

Background to the research

REDACTED delivered a presentation on the background to the research. Key points:

- 'Chronic pain' is defined as persistent or recurrent pain experienced for more than 3 months
- Based on NHS England 2017 data:
 - 34% experience chronic pain (12% high impact, 22% low impact)
 - Chronic pain incidence increases with age
 - Women more likely to report chronic pain
 - Higher incidence of chronic pain in deprived areas
- Analysis of responses to recent public consultation on draft framework for pain management service delivery showed there is high levels of support for vision and aims set out:
 - 93% support vision: Person-centred, effective and safe care that improves the quality of life and wellbeing of people with chronic pain in Scotland
 - 96% support Aim A: Person-centred care
 - 97% support Aim B: Timely access to care
 - 93% support Aim C: Safe, effective treatments
 - 92% support Aim D: Improving quality of life and wellbeing
- However respondents raised potential barriers to the implementation of the framework, including underfunded services, staffing shortages and poor understanding of chronic pain.
- Respondents also felt that the draft framework and aims required greater focus, specificity and ambition. In response, the SG developed an implementation plan for the framework for pain management service delivery with 18 actions, such as:
 - Developing a Pain Informed Care toolkit for health and care professionals
 - Establishing a Pain Service Managers Network
 - Promotion of safer, more effective prescribing for people with chronic pain
 - Establishing a national multidisciplinary Pain Education Group
- This work has been commissioned to gather views about the framework and implementation plan from a broad range of people across Scotland experiencing chronic pain, with a focus on seldom-heard voices who reflect the diversity of Scotland's chronic pain communities.

- The panel will sit within wider stakeholder engagement structures to support implementation of the framework. SG are also working with Health Improvement Scotland on a concurrent piece of consultation work which will have a more targeted focus on the implementation of the framework at the local level. This work will involve carers of people with chronic pain as well as those experiencing it.

TLB methodology

REDACTED provided an overview of TLB's proposed methodology:

- TLB will design a **sampling framework** to recruit a lived experience panel of 15 (with the intention to overrecruit a group of 22-25 to address any disengagement/attrition).
 - The sampling plan will be designed to reflect the demographics of the chronic pain population (as we understand it from NHS England data), e.g. more older people, more women than men
 - Additional criteria to be considered include:
 - Geography: representation from central belt, cities, rural, remote, highland and island communities
 - Treatment: self-treatment, clinical treatment
 - Mixture of conditions/sources of chronic pain
- TLB will design **screening tools** - Scottish Health Survey Questions will be used to inform these. Tools to include questions re potential panel members' demographics, conditions, treatment and whether they have been involved in chronic pain research/advocacy before.
- Once SG have signed off sampling framework and screening tools, TLB will begin recruitment phase. There are 2 recruitment streams:
 - Work with Taylor McKenzie (TM), recruitment experts
 - TM have a database with thousands of contacts who are interested in hearing about research opportunities. We will work with TM on targeted promotion of the opportunity to join the panel.
 - Personal/professional networks
 - TLB have contacts from past contracts and personal networks which we can use to identify potential panel members.
- Once the panel is assembled, TLB will offer different dates/times for workshops throughout the first half of August.
 - The panel will not be required to attend all workshops.
 - We will offer large groups, smaller groups and one-to-ones if requested.
 - All groups will be held online; one-to-ones will be offered via telephone, face-to-face or online.
 - SG and TLB will collaborate to design topic guides for workshops.
 - Participants will be sent a £50 Amazon voucher as a thank you for their participation in Phase 1.
- Workshops and one-to-ones will be transcribed and then data will be analysed.
- SG and TLB will agree exact reporting requirements (e.g. template, structure) at a later date. However it is agreed that final report will share findings from the panel's discussions and should be concise (30 page max), informative and engaging.

Timetable

Key milestones for Phase 1 of the project are set out below. Actions for SG are in **bold**:

Milestone	Date
TLB submit inception report	w/c 18 July
TLB submit sampling plan and screening tools	w/c 18 July
SG provide feedback on/sign off sampling plan and screening tools	w/c 25 July
TLB recruitment activity	w/c 25 July
TLB consultation with panel (workshops and one-to-ones)	Early-mid August
TLB submit high level findings/emerging themes document	w/c 29 August
TLB to submit draft report	w/c 12 September
SG provide feedback on draft report	w/c 19 September
TLB to submit final report	w/c 26 September
Government-led debate on the Pain Framework	Sep/Oct 22

Phase 2 milestones will be agreed after the conclusion of Phase 1.

Progress updates

Lorraine will provide weekly email updates followed by an online meeting or telephone call throughout the contract.

Contract

A hard copy of the contract was issued and signed by both parties prior to the inception meeting.

Invoicing schedule

TLB will send five invoices as set out in the ITT:

- 20% in July 2022 (after inception meeting)
- 20% in September 2022 (upon submission of Phase 1 final report)
- 20% at start of Phase 2 (date tbc)
- 30% after submission of Phase 2 report (date tbc)
- 10% April 2023 (end of contract)

Next steps

- SG to provide a PO number to allow TLB to submit first invoice.
- TLB to design sampling plan and submit to SG for approval.
- TLB to design screening tools to aid recruitment for the panel.

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From: Lorraine Simpson **REDACTED**@thelinesbetween.co.uk>
Sent: Friday, 22 July 2022 14:03
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED**@gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; louise.mcinnis2@gov.scot>; **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gmail.com
Subject: Re: Pain Management Lived Experience Panel - Inception report

Dear **REDACTED**

As promised, please find our draft sampling framework attached, plus a screener which aligns with the sampling framework.

The framework spans all the criteria discussed in the inception meeting - please review and let us know if there's anything else you want us to consider or, conversely, if anything we have included within the sample is not a priority for you and your colleagues.

We look forward to receiving your feedback - once the sample and screener is approved, we will progress to the next stage of recruiting panel members.

Best wishes

Lorraine

On Tue, Jul 19, 2022 at 11:49 AM <**REDACTED** @gov.scot> wrote:

Thank you very much indeed, **REDACTED**

I have returned from leave now and am happy to review the Sampling Framework when this is ready. Look forward to working with you all on this project.

Best regards,

REDACTED

REDACTED | Unit Head – Clinical Priorities | Healthcare Quality and Improvement
Scottish Government | St Andrew's House | Regent Road | Edinburgh | EH1 3DG
M: **REDACTED**

FOI - 202300342230 – document 6a

Scottish Government: Framework for Pain Management Service Delivery, Lived Experience Panel

Recruitment Screener: 15-22 people living with Chronic Pain

INFORMATION AND CRITERIA

Essential Criteria

All participants must:

- Have experience of chronic pain, which is defined as persistent or recurrent pain lasting longer than three months
- Be competent in spoken English without the assistance of an interpreter (though English does not have to be their first language)
- Be willing and able to talk about themselves in the context of the characteristic on which they have been recruited
- Feel comfortable contributing their opinion
- Not know any other participants in the project
- Be aged 18+ years
- Answer 'no' to statements asking about previous engagement with the development of the Framework for Pain Management Service Delivery

Hello! My name is _____ from [Taylor McKenzie recruitment agency/The Lines Between].

We are recruiting a panel of people with experience of living with chronic pain, to help inform the development of the Scottish Government's Framework for Pain Management Service Delivery.

It doesn't matter if you've never been or never heard of the Framework before; we are simply looking for people who have experience of living with chronic pain.

The panel will help the Scottish Government to understand how the Framework can best meet the needs and priorities of groups with chronic pain. We hope to build a panel of people with experience of living with chronic pain, and within this group, have diversity in terms of:

- Age and gender
- Location within Scotland
- Underlying conditions linked to chronic pain

We would like to ask you a few questions to see if you are suitable to join the panel. If you meet the panel criteria, your anonymized profile will be entered into a sampling pool from which the final sample for the lived experience panel will be drawn from.

[Note for SG: Details about GDPR and information storage/handling/deletion to be provided anyone who consents to participation in the screening process, and consent to be recorded before questions asked].

Before we begin, here's a summary about what being in the panel involves: If you meet the criteria for the panel and are invited to join the panel, a researcher will get in touch and arrange a time to tell you about the work, provide information about the Framework for Pain Management, answer your questions and find out about how you would like to take part and when you are available.

There are two stages of engagement. Each involves attending at least one online group session with 3 or 4 other participants, lasting 60-90 mins OR a one-to-one chat online by phone, or in person (depending on location).

- i) **August:** Engagement about vision, commitments and actions set out in the Framework
- ii) **Jan-Feb 2023:** Engagement about implementing the Framework

You will receive a £50 Amazon voucher at each stage of your engagement with the panel (£100 in total) as a thank you.

Are you happy to continue?

SCREENING QUESTIONS

Q1. Do you experience chronic pain, which is defined as:

persistent or recurrent pain lasting longer than three months

CODE ONE ONLY

Yes	1
No	2
Don't know	3
Prefer not to say	4

IF YES, Continue. For codes 2,3 and 4, THANK AND CLOSE.

Q2. Which of the following best describes your condition or illness?

CODE ALL THAT APPLY

Codes drawn from Sample Framework Sections 4 & 5

Q3. How is your pain treated?

CODE ALL THAT APPLY

Codes drawn from Sample Framework Section 6

Q4. Please answer yes or no to the following statements:

CODE ONE PER STATEMENT

	Yes	No
I have previously taken part in the Scottish Government's consultation on the Framework for Pain Management Service Delivery	Code 1	Code 2
I have previously engaged with another charity, advocacy or representative organization on issues to do with the Framework for Pain Management Service Delivery	Code 3	Code 4

RECRUITER: If answer is **YES TO EITHER OF THE OPTIONS** then **THANK & CLOSE.**

Q5. Which of the following age groups do you belong to?

CODE ONE ONLY.

17 or younger

1 **THANK & CLOSE**

Codes drawn from Sample Framework Section 3

Q6. Do you have access to a device (e.g. phone, tablet, or computer) that enables you to join a video call, and are you comfortable doing so in a group of with 3 or 4 other participants and research facilitators?

CODE ONE ONLY

Yes 1 **CONTINUE TO Q8**
No 2 **CONTINUE TO Q7**

Q7. Are you comfortable speaking on a 1:1 basis with a research via video or telephone call or in person?

CODE ONE ONLY.

Yes 1 **CONTINUE to Q8**
No 2 **THANK & CLOSE**

Q8. How would you describe your ethnicity?

CODE ONE ONLY

Codes drawn from Sample Framework Section 9

Q9. Which of the following options best describes your sexual identity?

CODE ONE ONLY

Codes drawn from Sample Framework Section 10

Q10. Which of the following areas do you live in?

CODE ONE ONLY

Codes drawn from Sample Framework Section 7

Q11. What is your postcode (full or first half)?

PLEASE STATE

Q12. What is your gender?

CODE ONE ONLY

Codes drawn from Sample Framework Section 2

Q13: Do you receive any of the following benefits?

CODE ALL THAT APPLY

Codes drawn from Sample Framework Section 8

Thank you for answering those questions. You are eligible to take part in this research. Our researchers are carefully selecting the final sample to ensure in spans a range of different criteria and will contact you shortly to confirm whether or not you have been selected to join the lived experience panel.

THANK AND CLOSE.

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chronic Pain Screening Framework: Sampling Framework v1

Section for Screener Questions	Key criteria	Target numbers out of 22	Detail	More info	Examples	Sampling Notes
1	Chronic Pain	22	Constant and/or on and off More than 3 months			Both criteria essential
2	Gender	9	Male			c. 40% of the sample to be male
		13	Female			
			Other			
			Prefer not to say			
3	Age	5	18-30			Over 50% of the sample to be 51+
		6	31-50			
		7	51-74			
		4	75+			
4	Underlying Diagnosis	2	Primary Pain	Pain in 1 or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional	Fibromyalgia.	Spread of pain points throughout the sample. Definitions taken from: https://www.nhsresearchscotland.org.uk/uploads/tinymce/National%20Outcomes%20Summary%20Report%20-%20pain.pdf Page 25

				<p>distress or significant functional disability (interference with activities of daily life and participation in social roles) and that cannot be better explained by another chronic pain condition.</p>		
		2	Cancer Pain	<p>Includes pain caused by the cancer itself (the primary tumour or metastases) and pain that is caused by the cancer treatment (surgical, chemotherapy, radiotherapy, and others).</p>	<p>Patients undergoing chemotherapy or palliative care</p>	

		2	Post surgical and post traumatic pain	Pain that develops after a surgical procedure or a tissue injury (involving any trauma, including burns) and persists at least 3 months after surgery or tissue trauma		
		2	Neuropathic pain	Caused by a lesion or disease of the somatosensory nervous system (pain linked to touch, senses or skin)	Shingles, Parkinson's, Multiple Sclerosis	
		2	Headache and orofacial pain	Headaches or pains to mouth, face or teeth	Migraines, dental issues	
		2	Visceral pain	Pain in the head/ neck/shoulders, stomach, or pelvis	Endometriosis or other gynaecological condition. IBS.	

		11	Musculoskeletal	Pain affecting bone(s), joint(s), muscle(s), or related soft tissue(s).	Arthritis, gout, osteoporosis	
5	Other conditions	3	Mental Illness			Would be useful if the sample can include people with experience of poor mental health
		5	Other			
6	Treatment pathway	3	Self-treatment	(E.g. using resources online or other knowledge)		At least 3 to have experience with self-treatment pathways
		19	Clinical Treatment	Treatment prescribed by GP, Nurse or pharmacist		
				Specialist NHS pain service at hospital		
				Private Services - Physio, Osteopath, Chiropractor, Acupuncture		
				Homeopath or other alterative medicines		
				Psychologist		

7	Geography	6	Cities			Spread across the sample - at least one in each geography type
		5	Highland and Islands			
		6	Central Belt			
		5	Other rural			
	Desirable Criteria					
8	Welfare		Universal Credit			Other notes - some diversity re: socio-economic status, sexual orientation, and ethnicity also desirable, but not essential criteria. Screening tool to collect data so diversity can be monitored.
			Jobseeker's Allowance			
			Employment and Support Allowance (ESA)			
			Income Support Allowance			
			Pension Credit			
			Housing Benefit			
			Discretionary Housing Payment			
			Personal Independence Payment (PIP)			
			Disability Living Allowance (DLA)			

			Attendance Allowance			
			Carer's Allowance			
			Working Tax Credit			
			Child Tax Credit			
			Working Families Tax Credit			
			Carers Allowance Supplement			
			Young Carer Grant			
			Child Disability Payment			
			Adult Disability Payment			
			Disabled Facilities Grant (Home modifications)			
			Other state benefits			
			I am not in receipt of any benefits			
9	Ethnicity		Mixed or Multiple Ethnic groups			
			Asian, Scottish Asian or British Asian			
			African, Scottish African or British African			
			Caribbean or Black			
			Other ethnic group			

			Prefer not to say			
10	Sexual orientation		Heterosexual/Straight			
			Gay/Lesbian			
			Bisexual			
			Other			
			Prefer not to say			

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From: REDACTED@gov.scot>
Sent: Monday, 25 July 2022 15:00
To: Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Cc: REDACTED@thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>; louise.mcinnis2@gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gmail.com
Subject: RE: Pain Management Lived Experience Panel - Inception report

Yes, that sounds good,
Thank you, Lorraine, we will work on that basis
Best,
REDACTED

From: Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Sent: 25 July 2022 14:39
To: REDACTED @gov.scot>
Cc: REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>; louise.mcinnis2@gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gmail.com
Subject: Re: Pain Management Lived Experience Panel - Inception report

Thanks, REDACTED

The ITT notes the SG will provide feedback on the recruitment specification within 2 working days, so on that basis, I asked our recruitment partner to expect confirmation of the sample by Wednesday morning, hoping we could start recruitment in earnest middle of the week. Does that timescale sound ok with you?

Best wishes

Lorraine

On Mon, Jul 25, 2022 at 1:29 PM <REDACTED @gov.scot> wrote:

Hello Lorraine,

Thank you very much for these. A colleague on our taskforce is going to review these with me. When do you need feedback/ sign off by please? I can look at these this PM, but just need to know how long I can give my colleague to review.
Best,

REDACTED

FOI - 202300342230 – document 8

From: REDACTED@gov.scot>
Sent: Tuesday, 26 July 2022 17:18
To: Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @thelinesbetween.co.uk; REDACTED@gov.scot REDACTED @gov.scot>; REDACTED @gov.scot>; louise.mcinnis2@gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gmail.com
Subject: RE: Pain Management Lived Experience Panel - Inception report

Hello Lorraine,
Please find attached excel document with tracked comments/ requested changes. These are indicated by a small red clickable triangle top right in the relevant cell. Please let me know if you can't access.
I've referred to the SHeS pain module Q's – attached here for info.
Very happy to chat through if easier. I have not put comments on the screener as that would then align to the sampling framework.
Best,
REDACTED

REDACTED | Unit Head – Clinical Priorities | Healthcare Quality and Improvement
Scottish Government | St Andrew's House | Regent Road | Edinburgh | EH1 3DG
M: REDACTED

FOI - 202300342230 – document 9

From: Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Sent: Thursday, 28 July 2022 14:28
To: REDACTED @gov.scot>
Cc: REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gmail.com; louise.mcinnis2@gov.scot>; REDACTED @gov.scot>
Subject: Re: Weekly progress update

That's ideal. Thanks REDACTED.

Best wishes

Lorraine

On Thu, Jul 28, 2022 at 1:54 PM <REDACTED@gov.scot> wrote:

Thank you, Lorraine.

We'll discuss priority areas for the first discussion/topic guide and come back to you early next week if that is sufficiently timely.

Best,

REDACTED

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: 28 July 2022 10:52
To: REDACTED@gov.scot>
Cc: REDACTED@thelinesbetween.co.uk>; REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@thelinesbetween.co.uk>; REDACTED@gmail.com>; REDACTED@gov.scot>; louise.mcinnis2@gov.scot>
Subject: Re: Weekly progress update

Hi REDACTED and REDACTED

Here is our weekly email update.

In summary, **the project is ON SCHEDULE**

So far, we have:

- Started work with Taylor McKenzie on recruitment processes
- Submitted a draft sample framework and screener and received your feedback
- Submitted our first invoice
- Submitted an inception report
- Reviewed the background documents you shared with our team
- Attended the inception meeting

Next week we will:

- Update you on the progress with recruitment
- Begin work to develop the tools for engaging with the Pain Panel
- Send you the final sample and screening tools (the screening tools are being finalised with input from Taylor McKenzie, now we have your comments on the sample - we have a meeting with them tomorrow to discuss some final points)

Actions/Questions for SG:

- We need to develop the engagement tools (discussion guides, etc). We have the consultation document, the consultation analysis report, and the implementation framework - these are very helpful. In his email last week, REDACTED noted that the *"Framework Implementation Plan sets out 18 Actions that we will seek to deliver to improve care and services for people with chronic pain. This...will be the main document to use with the Pain Panel in terms of gathering their views on priorities and approaches to implementation of the Actions/ outcomes"*. Before we get started on these tools - do you have any further steer on our work with the Pain

Panel in Stage 1, ie are there priority issues you wish us to focus on, or specific questions you need answers to?

My apologies, I missed **REDACTED** response to my question about the timing of weekly update calls. I'm afraid I am no longer available this afternoon, but we can start those calls next Thursday (or speak Mon-Weds anytime, if you'd like to speak sooner). I'll send the Teams update right after this email.

Don't hesitate to let me know if you have any questions.

Best wishes

Lorraine

FOI - 202300342230 – document 10

From: **REDACTED** @gov.scot>

Sent: Tuesday, 02 August 2022 14:17

To: Lorraine Simpson **REDACTED** @thelinesbetween.co.uk>

Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gmail.com; **REDACTED** @gov.scot>; louise.mcinnis2@gov.scot>

Subject: RE: Weekly progress update

Hello Lorraine,

Taking **REDACTED** off the correspondence for now. **REDACTED** will work alongside me on this and my colleagues **REDACTED** and Louise are also copied for info.

We would like to explore the following areas:

- **Nature of support and care people have received**, with particular emphasis on national services (e.g. national charities; digital services; phone services). Please include NHS inform: [Chronic pain - Illnesses and conditions | NHS inform](#)
- **Which elements of this care and support have been useful**. Which have not been useful. ((To note that we are also interested in local care and support here (including primary care, secondary care, peer support, community support, third sector). However as the HIS Engage work will explore this, it does not need a huge area in the TLB topic guide))
- **Nature of barriers to accessing this support** (consider [COM-B](#) or similar model – e.g. have these barriers been around capabilities, opportunities, motivation)
- **What's helped people access support?** - e.g. considering capability, opportunity, motivation (COM-B, above). What is preference?
- **Control of chronic pain** – what has helped people feel more in control of chronic pain (e.g. information, exercises, consultation, plan)
- **Current delivery and future value of Person Centred Care in support and care - [What matters to you](#)** – have people with chronic pain been asked what they need and want in regard to their support and care? Have they been asked about what matters to them within the larger context of their life? What would help them live well? What would they want someone giving them care or support to understand about living with chronic pain?
See also [Realistic Medicine – Shared decision making, reducing harm, waste and tackling unwarranted variation](#) – brief overview of Shared Decision Making and Personalised Approach To Care

What would help them participate in shared decision-making conversations, what resources or support might they need, what information might they need, how could/ should that be provided so its accessible, when should these conversations take place etc.

In all of the above, we are particularly interested in barriers/ opportunities for seldom heard groups – e.g. lower SEGs, ethnic minority groups, people with disabilities. Grateful if attention can be given to this both in development of the guide and in the analysis.

As mentioned, we are also undertaking insight gathering work with Healthcare Improvement Scotland Engagement (HIS Engage) on a more local/ regional basis. They have asked if they might have sight of your plans to consider as they move forwards. Are you okay for us to share your sample framework with them and discussion guide as it develops?

Best,
REDACTED

FOI - 202300342230 – document 11

From: Lorraine Simpson <**REDACTED**@thelinesbetween.co.uk>
Sent: Thursday, 04 August 2022 12:22
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gmail.com; **REDACTED** @gov.scot>; Louise.mcinnis2@gov.scot>
Subject: Re: Weekly progress update

Hi **REDACTED** and **REDACTED**

Apologies for the short delay with this update –[OUT OF SCOPE

Here is our weekly email update.

In summary, **the project is ON SCHEDULE**

This week, we have:

- Recruited 6 members of the pain panel that meet our criteria - a good start, and we are hopeful to have the full sample within a fortnight
- Arranged a session on 17th August to pilot the tools with a person with lived experience of chronic pain, to test them before they are used more widely with the Pain Panel
- Received your helpful update on the focus of engagement with the Pain Panel, and started work to develop the tools
- Submitted a draft sample framework and screener and received your feedback
- Received payment of our first invoice - thank you

- Sent you the final sample and screening tools - see links. (Please note Taylor McKenzie's screening tools have a few rogue capital letters; these are internal documents, but I've pointed out the typos to them)

Sampling -

Framework: <https://www.dropbox.com/s/sunw0v7x5482092/SG%20CP%20LEP%20Sample%20v2.xlsx?dl=0>

Screening Questionnaire: <https://www.dropbox.com/s/tud9qp2m6wdv9s7/Screening-20Chronic%20Pain%20v4.pdf?dl=0>

Next week we will:

- Update you on the progress with recruitment
- Continue work to develop the tools for engagement with the Pain Panel

Actions/Questions for SG:

- Nothing at the moment, but a heads up we'd like you to review the draft engagement tools once they are ready - we'll share them with you next week.
- You mentioned that HIS Engage wish to see tools etc, used and developed in this project - that's absolutely fine from our perspective. If they'd like a meeting with us to share learning or answer any questions, I'd be very happy to speak with them.

Don't hesitate to let me know if you have any questions - look forward to our catch-up later today.

Best wishes

Lorraine

FOI - 202300342230 – document 12

From: REDACTED@gov.scot>

Sent: Friday, 05 August 2022 10:22

To: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>

Cc: REDACTED@thelinesbetween.co.uk; REDACTED@gov.scot>; REDACTED@thelinesbetween.co.uk; REDACTED@gmail.com; louise.mcinnis2@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>

Subject: RE: Weekly progress update

Hello Lorraine,

Really good to catch up with you on our call yesterday, thank you.

You flagged that participants in one of the response options on the impact of chronic pain ('not at all') were hard to recruit (none as yet). We are still very keen to recruit from this group if possible, to learn from what we might term 'positive deviants'. We anticipate they might be found amongst people who practice e.g. mindfulness or engage in other forms of self-management.

We had discussed possibility of identifying these participants via third sector (especially organisations who promote these approaches), however on reflection we don't want to do that, as keen for this panel to be independently recruited.

On that basis, please could you proceed with the question as it stands and see if you/TMcK can find people?

However, please could you adjust the quotas/ targets on impact:

- 'A lot' – 7
- 'A little' – 11 – 12
- 'Not at all' – 2 – 3

In addition, pls could you update the question on gender moving forwards to allow for more response options:

- Male
- Female
- Transgender man
- Transgender woman
- Non-binary
- Prefer not to say

We also discussed the [implementation plan](#)... the areas for the discussion guide I had flagged of being as interest in the email below were inspired by the implementation plan, however grateful if you bear the implementation plan in mind more generally (particularly around Aim A) in developing the discussion guide.

In regard to building consensus, whilst experiences reported will be individual, still interested in building this, e.g. via Delphi method, when it comes to the recommendations from the panel back to Scottish Government.

As discussed, grateful if you can give us a few days (ideally 4 working days, 3 minimum) turnaround time on the discussion guide, so we can share with our Taskforce for feedback.

Best,
REDACTED

FOI - 202300342230 – document 13

From: Lorraine Simpson <**REDACTED**@thelinesbetween.co.uk>
Sent: Tuesday, 09 August 2022 14:34
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @gov.scot>; **REDACTED** @thelinesbetween.co.uk; **REDACTED** @thelinesbetween.co.uk>
Subject: Re: Weekly progress update

Hi **REDACTED**

Sorry, I should have confirmed receipt of this email - I don't work on Fridays and yesterday ran away with itself.

Yes, we're working to those targets now.

An interim update - we currently have 17 panel members, 1 of whom is in the 'not at all' impact category - we're focusing on this criteria in the final recruitment effort.

Best wishes

REDACTED

On Tue, Aug 9, 2022 at 2:10 PM <**REDACTED** @gov.scot> wrote:

Good afternoon **REDACTED**,

Just wanting to check in to make sure you were ok with the updates below re quotas/targets etc?

Thanks

REDACTED

Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 14

From: Lorraine Simpson <**REDACTED**@thelinesbetween.co.uk>
Sent: Thursday, 11 August 2022 11:52
To: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk>; **REDACTED** @thelinesbetween.co.uk>
Subject: Weekly progress update

Dear **REDACTED**, **REDACTED** and **REDACTED**,

Here is our weekly email update: **the project is ON SCHEDULE BUT WE MAY NEED TO SHIFT DEADLINES DEPENDING ON YOUR PREFERRED APPROACH TO ENGAGEMENT WITH THE PANEL (see below)**

This week, we have:

- Continued recruiting panel members – we now have 17 signed up to take part and are working with our recruitment partner to address some gaps in the sample through the final 5 participants
- Developed a first draft of the discussion guide and information sheet – this has prompted some internal discussion which we require your input on. We've been thinking about how best we can draw out themes and priorities from the panel discussions in the way that best meets your needs within the timeframe.

As you might know, the Delphi method takes a two (or more) stage approach. In the first stage, each group meets and discusses the topic, these discussions are qualitatively analysed so that key themes can be drawn out. These key themes are then brought to a second meeting, where each group has a further discussion before carrying out a prioritisation exercise. It's not possible to have both a discussion and prioritisation in one meeting - you need time to form the group, gain trust and analyse the discussions in between the meetings. Moreover, such a meeting would be very lengthy and people with chronic pain might find long meetings tiring.

Our original intention had been to use stage one of the work for the initial open discussions with each of the groups and to analyse these to provide high-level themes and recommendations in the report in September. We would then meet again with the groups in stage two to carry out a prioritisation exercise for the second report. This would allow nuanced reporting in Stage One which draws out, where applicable, themes relating to ethnicity, levels of pain, social deprivation and so on. However, it does mean that there would not be priorities at this stage. Would that meet your needs? If not, we suggest one of the following approaches:

1. Each group meets twice in Stage One. There would need to be approximately two weeks between the first and second discussion in order to give us time to draw out themes for the prioritisation exercise. This would push back the report submission by two weeks.
2. The group meets once in Stage One and then takes part in the prioritisation exercise where they would log in online as individuals. This has the potential to be quicker, however there might be less engagement from participants and there would be no opportunity for discussion between participants. It does have the advantage of allowing the participant to do this in a time that suits them. The report would also need to be pushed back by a week or so.

Next week we will:

- Update you on the progress with recruitment
- Continue work to develop the tools for engagement with the Pain Panel - reflecting any steer provided by you this afternoon
- We have a pilot session pencilled in to test the tools with a person with lived experience of chronic pain on 17th August - again, we can shift this depending on your feedback re: the preferred approach

Actions/Questions for SG:

- Please share your feedback reon the preferred approach re the delphi method
- Review the draft information sheet and discussion guide once they are ready (we note you need at least 4 working days to review and provide feedback)

Don't hesitate to let me know if you have any questions. I'm looking forward to our catch-up later today, which **REDACTED** and **REDACTED** will be joining.

Best wishes,

Lorraine
Lorraine Simpson Managing Director | The Lines Between Ltd. | Accessible Social Research
|

FOI - 202300342230 – document 15

From: REDACTED@gov.scot>

Sent: Thursday, 11 August 2022 14:06

To: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>; REDACTED @gov.scot>; REDACTED @gov.scot>

Cc: REDACTED @thelinesbetween.co.uk>; REDACTED @thelinesbetween.co.uk>
Subject: RE: Weekly progress update

Hi Lorraine

Many thanks for the update. Looking forward to discussing the options our have given later today at the catch up meeting. Below is the timeline from the inception report which will help me to visualise better proposed changes to delivery.

thanks

Milestone	Date
TLB submit inception report	w/c 18 July
TLB submit sampling plan and screening tools	w/c 18 July
SG provide feedback on/sign off sampling plan and screening tools	w/c 25 July
TLB recruitment activity	w/c 25 July
TLB consultation with panel (workshops and one-to-ones)	Early-mid August
TLB submit high level findings/emerging themes document	w/c 29 August
TLB to submit draft report	w/c 12 September
SG provide feedback on draft report	w/c 19 September
TLB to submit final report	w/c 26 September
Government-led debate on the Pain Framework	Sep/Oct 22

REDACTED
Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 16

From: REDACTED@thelinesbetween.co.uk>
Sent: Friday, 12 August 2022 16:28
To: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>
Cc: REDACTED@thelinesbetween.co.uk>; REDACTED@thelinesbetween.co.uk>
Subject: Chronic pain panel - draft tools

Hi REDACTED, REDACTED and REDACTED,

As agreed in our conversation yesterday, I am sharing with you the first draft of the research tools for the chronic pain panel project. There are 2 documents attached: a discussion guide, and an information sheet which will be emailed to the panel in advance of the workshops. Please feel free to track changes and leave comments in the documents, or provide us with more general comments via email.

Look forward to receiving your feedback.

Have a lovely weekend.

REDACTED
REDACTED | Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: REDACTED
www.thelinesbetween.co.uk | @thelinesbetweet

FOI - 202300342230 – document 16a

Scottish Government Pain Management Lived Experience Panel

Discussion Guide

Introduction (5 mins)

Thank you for attending.

My name is X and this is my colleague X. We are researchers for The Lines Between, a social research agency based in Edinburgh.

As you know, this is the first meeting of the panel. What all of you have in common is that you have experience of living with chronic pain, although it might be for different reasons or be of a different severity. The Scottish Government are very keen to hear recommendations from you on how they can improve services for people with chronic pain.

Here's how the session today will work:

- We have planned a 90-minute session, so we'll be finished by xx at the latest.
- We will also be using an online whiteboard [Facilitators to spend a few minutes showing the group how it works and testing that everyone can use it]. Please feel free to add your thoughts onto the whiteboard as well as joining in on the discussion.
- We will all take a 10-minute comfort break about halfway through the session, but if you need a break at any other time then do take one.
- We're all at home so if you have family or pets in the background or the doorbell goes, please don't worry.
- Please be tolerant and respectful of opinions that might differ from yours, and please don't share other people's views outside this space – people need to feel they can be open and trust their comments won't be shared with anyone else.
- You only need to contribute where you feel comfortable doing so. If you don't want to discuss something, you don't have to. If you'd rather email us your thoughts after the discussion is over, you can do that too.
- We are keen to hear the lived experiences of a diverse range of people, and so have involved people with different backgrounds, ages, ethnicities, genders etc. Don't feel that you have to provide detail about this if you don't want to, but if you feel your experiences have been affected by those aspects of your identity, we would be really interested to hear that.
- I'm going to record the discussion to ensure I can concentrate on what you're saying and we have an accurate record of everyone's input. Once we have finished the project, the recording will be deleted. Everything you say will be kept confidential, but we may use some of your anonymised quotes in our report. Are there any objections to this?
- Don't worry if that was a lot to take in – the details are all in your participant information sheet, which was sent to everyone in advance.
- Any questions before we get started?

Energiser

(5 mins)

We're going to start with a little exercise which is to ease us in and help us get to know each other a little better.

We'll go round everyone now and if you can tell me:

- your name
- where in Scotland you live
- ice-breaker exercise – to be decided on, but will involve the whiteboard to get everyone familiar with using it

Note for SG:

The questions set out in the rest of the guide are intended as general points of discussion which will be raised in the groups, with prompts used as needed. We will guide the groups through the discussion points in an informal, relaxed setting. We won't put people on the spot and ask them to share an answer to every question, but instead will allow the discussion to flow and encourage participants to follow on from one another's contribution as we move through the guide (with facilitators ensuring the discussion remains relevant and on theme).

Experiences of support mins)

(20

We'd like to start by discussing the support and care currently available for people who are experiencing chronic pain.

What is your understanding of the support available for people living with chronic pain?

Prompts if not raised by group:

- *Medical – treatments, medication*
- *Practical – financial, home adaptations, travel*
- *Emotional support- therapy, mental health support*

What are your thoughts on the support available through different pathways or sources?

Prompts if not raised by group:

- *Public health services*
- *Private health care*
- *Charities or third sector organisations*
- *Digital services including NHS Inform*
- *Phone services e.g. 111*

What does good, effective support for chronic pain look like to you? Please use the whiteboard to put forward some key words, and we'll talk about them as a group.

Is there anything that makes you feel more in control of chronic pain?

Prompts if not raised by group:

- *Information*
- *Exercises*
- *Consultation*
- *Private health care*

Are there any positive experiences of support that anyone can share? What can be learned from those interactions?

Barriers to accessing support (20 mins)

We'd like to learn more about the challenges and barriers that people with chronic pain face when accessing support for their condition.

What makes it difficult for people to access care and support for chronic pain?

Prompts if not raised by group:

- *Physical/practical barriers, like distance, service operating times, waiting lists, lack of available appointments*
- *Emotional barriers, like lack of motivation, negative past experiences*

Is there anything related to identity, personal characteristics or circumstances which acts as a barrier or makes it difficult for people with chronic pain to access support?

Prompts if not raised by group:

- *Age*

- Gender
- Ethnicity
- Sexual orientation
- Religion
- Disability
- Low income

Enablers to accessing support (10 mins)

We've discussed the challenges people with chronic pain might face in accessing support. Now I'd like you to consider the other side – what makes it easier for people to access support?

What should services prioritise in their care and support offer?

Prompts if not raised by group:

- Choice
- Speed
- Accessibility
- What qualities should practitioners have?

Person-centred care (25 mins)

Next, we'll talk about the idea of 'person-centred care'. Is this a term that people are familiar with? Don't worry if not, I'll talk you through what it means.

Person-centred care

In health care, person-centred care is a practice in which patients actively participate in their own medical treatment in close cooperation with their health professionals.

Here is a short animation produced by the Nursing and Midwifery Council which explains what we mean by person-centred care, giving some examples of how it works in practice.

<https://www.nmc.org.uk/standards/code/code-in-action/person-centred-care/>

What do you think about this approach?

Prompts if not raised by group:

- Is it an approach you support/agree with? Why?
- Does this reflect your experiences of support?
- Important for building trust?
- Do you think it leads to better outcomes?

An element of this approach is that practitioners take the time to get to know more about you and your circumstances.

To do this, they might have a 'What matters to you?' conversation with you. This is a discussion with a medical professional where you are asked about what you need and want in regard to support and care, and what would help you to 'live well'.

What are your thoughts this?

Prompts if not raised by group:

- *Has anyone got experience of this type of conversation?*
- *Is this something you think is important?*
- *What would you be comfortable sharing in this instance?*
- *What could practitioners do to support you and make it easier to take part in this conversation?*

Another element of person-centred care is that all tests, procedures and treatments are explained well in a way that makes sense to you, and you get the chance to ask questions after.

How do you feel about this?

Prompts if not raised by group:

- *Has this been your experience in the past?*
- *Is this something that is important to you?*
- *What information should be provided?*
- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

Person-centred care also means that patients are involved in decisions about their own health care. Is this important to you?

Prompts if not raised by group:

- *What would help you to participate in shared decision-making conversations?*
- *When should these conversations take place?*
- *What resources and information should be provided?*
- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

What would you want someone who is providing care or support to understand about living with chronic pain?

Close

(5 min)

- Thank everyone for their participation and contribution
- Remind the group they can email us with any further thoughts if they wish
- Explain we will send £50 as a thank you
- Check everyone is happy to remain involved in the next discussion and confirm we will be in touch soon

FOI - 202300342230 – document 16b

Scottish Government Pain Management Lived Experience Panel

Information sheet

August 2022

Introduction

The Lines Between is an independent research agency based in Edinburgh. We have been commissioned by the Scottish Government to recruit a panel of people with lived experience of chronic pain. We want to engage people from a range of backgrounds and places in Scotland so that we can ensure different views are heard. The Scottish Government is keen that people with chronic pain are involved on an ongoing basis in informing the implementation and delivery of the aims and commitments of the new Framework for Chronic Pain Service Delivery. This will help to ensure that future services are designed in a way that best meets the needs of its users.

If you want to read the Framework you can do so by clicking on the following link.
<https://www.gov.scot/publications/draft-framework-chronic-pain-service-delivery>

About the lived experience panel

We will meet with you as part of a group to listen to your views on how chronic pain services can best be made person-centred, timely, accessible, and safe and effective to improve the quality of lives of people with chronic pain. Based on your views, we will make recommendations to the Scottish Government to inform the implementation of the pain management framework in Scotland from a lived experience perspective.

Your role in the research

You have been invited to take part in two online group discussions. The first one is in August 2022, and the second will be a few weeks after. Each discussion will be held on Zoom and take approximately 90 minutes. If it is difficult for you to take part in a group discussion, we can arrange a one-to-one interview with you instead.

After the group discussion is over, if you feel that you have something else you'd like to say, you can email us with any further points that you would like to make.

The first discussion will cover:

- Your experiences of accessing support for your chronic pain condition
- What has and hasn't worked well about approaches taken in the past
- What makes it difficult to access support
- What can be put in place to make it easier to access support
- Your thoughts on 'person-centred care' – where patients actively participate in their own medical treatment in close cooperation with their health professionals

The purpose of this discussion is to learn how people with chronic pain think services in Scotland could be improved. There are no right or wrong answers. Your answers will be collated with feedback from approximately 15 other people with chronic pain. Our team will then analyse this information and make recommendations to the Scottish Government based on our findings.

After the group discussion (or interview) you will be given £50 as thank you for your time and input.

We will contact you in a few weeks' time to ask you if you are happy to take part in a second discussion. This second date hasn't been confirmed but we will let you know as soon as we can. A second payment of £50 will be made after the second discussion.

Important information for you to know

These are some other things to consider before taking part:

- **Taking part is voluntary.** You do not have to take part if you do not want to.
- **The feedback you provide will remain anonymous.** We won't share any details that identify you (like your name) with anyone else. The feedback you provide will never be linked back to you, and if we use something you say in our report it will not be labelled with your name.
- **You decide how much you share.** You don't have to answer all the questions or share anything personal unless you want to.
- **You can change your mind at any time.** You can choose to withdraw at any time before, during or after taking part in the research, and do not have to give a reason for doing so. If this is after we've spoken with you, just email us (contact details are at the end of this information sheet), tell us you would like to withdraw and we will delete your data.
- **With your permission, we will audio record the discussion.** This is so we can transcribe the call and ensure your feedback is documented fully and accurately. The recording will be held securely and deleted at the end of the research contract.

Data protection

We will collect the following personal information from you:

- Your name
- Your email address
- Your telephone number (only if you are taking part in an interview over the phone)
- The views and experiences you share during the discussion

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- Ask us to see the personal information you give we hold about you.
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Lorraine Simpson, Managing Director

The Lines Between

3 Piershill Place, Edinburgh, EH8 7EH

Phone: 0131 235 2012

Email: **REDACTED**@thelinesbetween.co.uk

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Information Commissioner's Office

Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>

Contact details

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Lorraine Simpson

Phone: 0131 235 2012

Email: **REDACTED** @thelinesbetween.co.uk

FOI - 202300342230 – document 17

From: REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 18 August 2022 09:30
To: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>
Cc: REDACTED@thelinesbetween.co.uk>; Lorraine Simpson
<REDACTED@thelinesbetween.co.uk>
Subject: Chronic pain - weekly progress update

Dear REDACTED, REDACTED and REDACTED,

Here is our weekly email update: **the project is ON SCHEDULE**

Since our last update, we have:

- Submitted a first draft of tools to you for review - feedback is due by COP tomorrow
- Completed the recruitment of our panel – we now have the target 15 signed up to take part in a workshop, and a bank of 7 alternates in case of no-shows/withdrawal. We can confirm the panel meets all the sampling criteria agreed
- Completed a pilot interview testing the tools which went well
- Set dates and times for the workshops next week
 - Tuesday 23rd - 2 afternoon groups
 - Wednesday 24th - evening group

Next week we will:

- Refine the information sheet and discussion guide based on our pilot interview and your feedback
- Send out the information sheet to the panel
- Hold the first set of workshops
- Have the groups transcribed
- Begin analysis as soon as the transcripts are complete

Actions/Questions for SG:

- Nothing outstanding at the moment
- From our side, I would be happy for us to leave this afternoon's update meeting and allow you some extra time to review the tools. But let me know if you'd still be keen to go ahead with it and of course I will be there.

Don't hesitate to let me know if you have any questions.

All the best,

REDACTED

--

REDACTED

| Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: REDACTED

FOI - 202300342230 – document 18

From: REDACTED@gov.scot>
Sent: Friday, 19 August 2022 11:46
To: REDACTED @thelinesbetween.co.uk>; REDACTED @gov.scot>; REDACTED @gov.scot>
Cc: 'Lorraine Simpson' REDACTED @thelinesbetween.co.uk>; REDACTED margaret@thelinesbetween.co.uk>
Subject: RE: Chronic pain panel - draft tools

Hi,

Will correct attachments. Please delete earlier email if arrived.

Thanks and apologies for the confusion

KR

REDACTED
Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

From: REDACTED
Sent: Friday, 19 August 2022 11:41
To: REDACTED @thelinesbetween.co.uk>; REDACTED @gov.scot>; REDACTED @gov.scot>
Cc: 'Lorraine Simpson' REDACTED @thelinesbetween.co.uk>; REDACTED margaret@thelinesbetween.co.uk>
Subject: RE: Chronic pain panel - draft tools

Hi **REDACTED**

Please see attached with comments.

For our records could you send over the final documents please?

Kindest regards,

REDACTED
Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 18a

Scottish Government Pain Management Lived Experience Panel

Discussion Guide

Introduction

(5 mins)

Thank you for attending.

My name is X and this is my colleague X. We are researchers for The Lines Between, a social research agency based in Edinburgh.

As you know, this is the first meeting of the panel. What all of you have in common is that you have experience of living with chronic pain, although it might be for different reasons or be of a different severity. The Scottish Government are very keen to hear recommendations from you on how they can improve services for people with chronic pain.

Here's how the session today will work:

- We have planned a 90-minute session, so we'll be finished by xx at the latest.
- We will also be using an online whiteboard [Facilitators to spend a few minutes showing the group how it works and testing that everyone can use it]. Please feel free to add your thoughts onto the whiteboard as well as joining in on the discussion.
- We will all take a 10-minute comfort break about halfway through the session, but if you need a break at any other time then do take one.
- We're all at home so if you have family or pets in the background or the doorbell goes, please don't worry.
- Please be tolerant and respectful of opinions that might differ from yours, and please don't share other people's views outside this space – people need to feel they can be open and trust their comments won't be shared with anyone else.
- You only need to contribute where you feel comfortable doing so. If you don't want to discuss something, you don't have to. If you'd rather email us your thoughts after the discussion is over, you can do that too.
- We are keen to hear the lived experiences of a diverse range of people, and so have involved people with different backgrounds, ages, ethnicities, genders etc. Don't feel that you have to provide detail about this if you don't want to, but if you feel your experiences have been affected by those aspects of your identity, we would be really interested to hear that.
- I'm going to record the discussion to ensure I can concentrate on what you're saying and we have an accurate record of everyone's input. Once we have finished the project, the recording will be deleted. Everything you say will be kept confidential, but we may use some of your anonymised quotes in our report. Are there any objections to this?
- Don't worry if that was a lot to take in – the details are all in your participant information sheet, which was sent to everyone in advance.
- Any questions before we get started?

Commented [NM1]:

- Please add to list of 'backgrounds, ages,' etc that we are equally keen to hear from people with chronic pain with low impact on their daily life and those for whom it has high impact on daily life.
- Request to add: We are also keen to hear any positive experiences

Energiser

(5 mins)

We're going to start with a little exercise which is to ease us in and help us get to know each other a little better.

We'll go round everyone now and if you can tell me:

- your name
- where in Scotland you live
- ice-breaker exercise – to be decided on, but will involve the whiteboard to get everyone familiar with using it

Note for SG:

The questions set out in the rest of the guide are intended as general points of discussion which will be raised in the groups, with prompts used as needed. We will guide the groups through the discussion points in an informal, relaxed setting. We won't put people on the spot and ask them to share an answer to every question, but instead will allow the discussion to flow and encourage participants to follow on from one another's contribution as we move through the guide (with facilitators ensuring the discussion remains relevant and on theme).

Commented [NM2]: Understood, however can you confirm you will encourage quieter respondents to speak up by e.g. addressing them individually if needed?

Experiences of support (20 mins)

We'd like to start by discussing the support and care currently available for people who are experiencing chronic pain.

What is your understanding of the support available for people living with chronic pain?

Prompts if not raised by group:

- Medical – treatments, medication
- Practical – financial, home adaptations, travel
- Emotional support- therapy, mental health support

What are your thoughts on the support available through different pathways or sources?

Prompts if not raised by group:

- Public health services
- Private health care
- Charities or third sector organisations or community groups
- Digital services including online information from the NHS
- Phone services e.g. 111

Commented [NM3]: "What organisations or services have you used to get support for your chronic pain and what did you think of them"?

Commented [NM4R3]: prefer to avoid mention of pathways for lay audiences

Commented [JO5]: may need to prompt this for some cultural groups where there is lots of community-based support

What does good, effective support for chronic pain look like to you? Please use the whiteboard to put forward some key words, and we'll talk about them as a group.

Commented [JO6]: just suggesting this as people may not know what NHS inform is (sadly)

Is there anything that makes you feel more in control of chronic pain?

Prompts if not raised by group:

- Information
- Exercises
- Consultation with healthcare providers
- Complementary therapies e.g. massage, Tai Chi, chair yoga etc
- Peer support
-

Are there any positive experiences of support that anyone can share? What can be learned from those interactions?

Barriers to accessing support (20 mins)

We'd like to learn more about the challenges and barriers that people with chronic pain face when accessing support for their condition.

What makes it difficult for people to access care and support for chronic pain?

Prompts if not raised by group:

- Physical/practical barriers, like distance, service operating times, waiting lists, lack of available appointments, childcare, travel costs, time off work
- Emotional barriers, like lack of motivation, negative past experiences, fear, anxiety or mental stress
- Lack of clear understanding or information on where to go for help, when to look for it, and how to access it

Is there anything about your own background, identity or circumstances which you think make it harder to access support for chronic pain?

Prompts if not raised by group:

- Age
- Gender
- Ethnicity
- Sexual orientation
- Religion
- Disability
- Low income

Commented [JO7]: I think important to include this prompt as people report feeling like their healthcare journey is uncoordinated and they 'bounce' about the system or get 'lost'

Commented [NM8]: If this question does not elicit examples and instead leads to general opinions on this, can we probe for examples... e.g what makes you say this or do you have an example of this

Commented [JO98]: In the opening piece you flag that you'll be asking about identity and its potential impact so think you can perhaps be more explicit with participants here e.g. "Is there anything about your own background or current circumstances which you think make it harder to access...support"

Commented [NM108]: Okay, yes

Enablers to accessing support (10 mins)

We've discussed the challenges people with chronic pain might face in accessing support. Now I'd like you to consider the other side – what makes it easier for people to access support?

What should services prioritise in their care and support offer?

Prompts if not raised by group:

- Choice
- Speed
- Accessibility / proximity
- What qualities, knowledge and skills should practitioners have?

Commented [NM11]: For analysis, will you be able to break down whether responses relate to primary care, secondary care or third sector where applicable?

Person-centred care (25 mins)

Next, we'll talk about the idea of 'person-centred care'. Is this a term that people are familiar with? Don't worry if not, I'll talk you through what it means.

Person-centred care

- Person-centred care is a practice by which healthcare professionals and services support people to develop the knowledge and confidence to make informed decisions and be involved in their own health and care.

- Care and support should be **personalised** based on the things that are important to the person and help them reach their goals.

Here is a short animation produced by the Nursing and Midwifery Council which explains what we mean by person-centred care, giving some examples of how it works **in practice.**

<https://www.nmc.org.uk/standards/code/code-in-action/person-centred-care/>

- **Does this reflect your experiences of support?**

An element of person-centred care is that **healthcare staff** take the time to get to know more about you and your circumstances.

To do this, they might have a ‘What matters to you?’ conversation with you. This is a discussion with a medical professional where you are asked about what you need and want in regard to support and care, and what would help you to ‘live well’. and do the things that you would normally do that matter to you.

- *Has anyone got experience of this type of conversation?*
- *Is this something you think is important?*
- *What would you be comfortable sharing in this instance?*
- *Where and when would you want to do this? (face to face, on the phone, video call)*
- *What could practitioners do to support you and make it easier to take part in this conversation?*

Another element of person-centred care is that all medicines, treatments or advice and options to help you improve your health, are explained well in a way that makes sense to you, and you get the chance to ask questions after.

How do you feel about this?

Prompts if not raised by group:

- *Has this been your experience in the past?*
- *Is this something that is important to you?*
- *What information should be provided?*
- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

Person-centred care also means that patients are involved in decisions about their own health care. Is this important to you?

Prompts if not raised by group:

- *What would help you to participate in shared decision-making conversations?*
- **When and where** *should these conversations take place?*
- *What resources and information should be provided?*
- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

What would you want someone who is providing care or support to understand about living with chronic pain?

Commented [NM12]: When playing this video please can you ensure it is stopped well before 'next; end of life care'

Commented [JO13]: this is used throughout but not sure people will know what it means: suggest NHS staff or healthcare staff

Close

(5 min)

- Thank everyone for their participation and contribution
- Remind the group they can email us with any further thoughts if they wish
- Explain we will send £50 as a thank you
- Check everyone is happy to remain involved in the next discussion and confirm we will be in touch soon

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Scottish Government Pain Management Lived Experience Panel

Information sheet

August 2022

Introduction

The Lines Between is an independent research agency based in Edinburgh. We have been commissioned by the Scottish Government to recruit a panel of people with lived experience of chronic pain. We want to engage people from a range of backgrounds and places in Scotland so that we can ensure different views are heard. The Scottish Government is keen that people with chronic pain are involved on an ongoing basis in informing the implementation and delivery of the aims and commitments of the new Framework for Chronic Pain Service Delivery. This will help to ensure that future services are designed in a way that best meets the needs of its users.

If you want to read the Implementation Plan which sets out the Actions in the Framework you can do so by clicking on the following link.

<https://www.gov.scot/publications/framework-pain-management-service-delivery-implementation-plan/>

Commented [SR14]: suggest we add in link to implementation plan too as this links to more updated wording

Commented [JO15]: Yes - agree and have updated.

About the lived experience panel

We will meet with you as part of a group to listen to your views on how chronic pain services can best be made person-centred, timely, accessible, and safe and effective to improve the quality of lives of people with chronic pain. Based on your views, we will make recommendations to the Scottish Government to inform the implementation of the pain management framework in Scotland from a lived experience perspective.

Your role in the research

You have been invited to take part in two online group discussions. The first one is in August 2022, and the second will be a few weeks after. Each discussion will be held on Zoom and

take approximately 90 minutes. If it is difficult for you to take part in a group discussion, we can arrange a one-to-one interview with you instead.

After the group discussion is over, if you feel that you have something else you'd like to say, you can email us with any further points that you would like to make.

The first discussion will cover:

- Your experiences of accessing support for your chronic pain condition
- What has and hasn't worked well about approaches taken in the past
- What makes it difficult to access support
- What can be put in place to make it easier to access support
- Your thoughts on 'person-centred care' – where healthcare practitioners work together with you to tailor services to support what matters most to you.

Commented [JO16]: More info here: importantly it's not about making medical choices, it's about having the knowledge and confidence to make informed decisions on care. [Person centred care - NES \(scot.nhs.uk\)](https://www.scot.nhs.uk/person-centred-care/)

The purpose of this discussion is to learn how people with chronic pain think services in Scotland could be improved. There are no right or wrong answers. Your answers will be collated with feedback from approximately 15 other people with chronic pain. Our team will then analyse this information and make recommendations to the Scottish Government based on our findings.

After the group discussion (or interview) you will be given £50 as thank you for your time and input.

We will contact you in a few weeks' time to ask you if you are happy to take part in a second discussion. This second date hasn't been confirmed but we will let you know as soon as we can. A second payment of £50 will be made after the second discussion.

Important information for you to know

These are some other things to consider before taking part:

- **Taking part is voluntary.** You do not have to take part if you do not want to.
- **The feedback you provide will remain anonymous.** We won't share any details that identify you (like your name) with anyone else. The feedback you provide will never be linked back to you, and if we use something you say in our report it will not be labelled with your name.
- **You decide how much you share.** You don't have to answer all the questions or share anything personal unless you want to.
- **You can change your mind at any time.** You can choose to withdraw at any time before, during or after taking part in the research, and do not have to give a reason for doing so. If this is after we've spoken with you, just email us (contact details are at the end of this information sheet), tell us you would like to withdraw and we will delete your data.

- **With your permission, we will audio record the discussion.** This is so we can transcribe the call and ensure your feedback is documented fully and accurately. The recording will be held securely and deleted at the end of the research contract.

Data protection

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Phone: 0131 235 2012

Email: **REDACTED** @thelinesbetween.co.uk

FOI - 202300342230 – document 19

From: **REDACTED**@thelinesbetween.co.uk>

Sent: Monday, 22 August 2022 11:21

To: **REDACTED** @gov.scot>

Cc: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; Lorraine Simpson **REDACTED** @thelinesbetween.co.uk>; **REDACTED** @thelinesbetween.co.uk>

Subject: Re: Chronic pain panel - draft tools

Hi **REDACTED**,

Thank you for the clear and concise feedback on the research tools. We've addressed the edits, and made a few minor changes based on our pilot interview from last week.

I've attached the final versions of each which will be used for the workshops this week.

Kind regards,

REDACTED

FOI - 202300342230 – document 19a

Scottish Government Pain Management Lived Experience Panel Information sheet

August 2022

Introduction

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- • What makes it difficult to access support
- • What can be put in place to make it easier to access support
- • Your thoughts on 'person-centred care' – where healthcare practitioners work with you to ensure you have the knowledge and confidence to make informed decisions on care

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Helpline number: 0303 123 1113
ICO website: <https://www.ico.org.uk>

Contact details

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Lorraine Simpson
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Email: **REDACTED** @thelinesbetween.co.uk

FOI - 202300342230 – document 19b

Scottish Government Pain Management Lived Experience Panel

Discussion Guide

Introduction

(5 mins)

Thank you for attending. My name is X and this is my colleague X. We are researchers for The Lines Between, a social research agency based in Edinburgh.

As you know, this is the first meeting of the panel. What all of you have in common is that you have experience of living with chronic pain, although it might be for different reasons or be of a different severity. The Scottish Government is very keen to hear recommendations from you on how they can improve services for people with chronic pain.

Here's how the session today will work:

- We have planned a 90-minute session, so we'll be finished by xx at the latest.
- We will also be using an online whiteboard **Note for facilitator - spend a few minutes showing the group how it works and testing that everyone can use it** Please feel free to add your thoughts onto the whiteboard as well as joining in on the discussion.
- We will all take a 10-minute comfort break about halfway through the session, but if you need a break at any other time then do take one.
- We're all at home so if you have family or pets in the background or the doorbell goes, please don't worry.
- Please be tolerant and respectful of opinions that might differ from yours, and please don't share other people's views outside this space.
- You only need to contribute where you feel comfortable doing so. If you don't want to discuss something, you don't have to. If you'd rather email us your thoughts after the discussion is over, you can do that too.
- We are keen to hear the lived experiences of a diverse range of people, and so have involved people from different backgrounds, ages, ethnicities, genders etc. Don't feel that you have to provide detail about this if you don't want to, but if you feel your experiences have been affected by those aspects of your identity, we would be really interested to hear that. We are also keen to hear any positive experiences of accessing support you may have.
- Our panel also has representation from people with different conditions and experiences of chronic pain. We are keen to hear both from people whose chronic pain has a high impact on their daily life, and those whose condition has a low impact on their life, so please don't worry if there are others whose experiences of chronic pain are different to yours.
- I'm going to record the discussion to ensure I can concentrate on what you're saying and we have an accurate record of everyone's input. Once we have finished the project, the recording will be deleted. Everything you say will be kept confidential, but we may use some of your anonymised quotes in our report. Are there any objections to this?
- Don't worry if that was a lot to take in – the details are all in your participant information sheet, which was sent to everyone in advance.
- Any questions before we get started?

Energiser

(5 mins)

We're going to start with a little exercise which is to ease us in and help us get to know each other a little better.

Can you tell me

- your name
- where in Scotland you live
- **ice-breaker exercise – to be decided on, but will involve the whiteboard to get everyone familiar with using it**

Note for SG:

The questions set out in the rest of the guide are intended as general points of discussion which will be raised in the groups, with prompts used as needed. We will guide the groups through the discussion points in an informal, relaxed setting. We won't put people on the spot and ask them to share an answer to every question, but instead will allow the discussion to

flow and encourage participants to follow on from one another's contribution as we move through the guide (with facilitators ensuring the discussion remains relevant and on theme).

Experiences of support (mins)

(20

We'd like to start by discussing the support and care currently available for people who are experiencing chronic pain.

What is your understanding of the support available for people living with chronic pain?

Prompts if not raised by group:

- *Medical – treatments, medication*
- *Practical – financial, home adaptations, travel*
- *Emotional support- therapy, mental health support*

What organisations or services have you used to get support for your chronic pain and what did you think of them?

Prompts if not raised by group:

- *Public health services*
- *Pain clinics*
- *Private health care*
- *Alternative or complementary therapies*
- *Charities or third sector organisations or community groups*
- *Digital services including online information from the NHS*
- *Phone services e.g. 111*
- *Online support or apps*

What does good, effective support for chronic pain look like to you? Please use the whiteboard to put forward some key words, and we'll talk about them as a group.

Is there anything that makes you feel more in control of chronic pain?

Prompts if not raised by group:

- *Information*
- *Exercises*
- *Consultation with healthcare providers*
- *Complementary therapies e.g. massage, Tai Chi, chair yoga etc*
- *Peer support*
- *Disability aids*

Are there any positive experiences of support that anyone can share?

Barriers to accessing support (mins)

(20

We'd like to learn more about the challenges and barriers that people with chronic pain face when accessing support for their condition.

What makes it difficult for people to access care and support for chronic pain? Have you had challenges? What kind?

Prompts if not raised by group:

- *Physical/practical barriers, like distance, service operating times, waiting lists, lack of available appointments, childcare, travel costs, time off work*
- *Emotional barriers, like lack of motivation, negative past experiences, fear, anxiety or mental stress*
- *Lack of clear understanding or information on where to go for help, when to look for it, and how to access it*

Is there anything about your own background, identity or circumstances which you think make it harder to access support for chronic pain?

Prompts if not raised by group:

- *Age*
- *Gender*
- *Ethnicity*
- *Sexual orientation*
- *Religion*
- *Disability*
- *Low income*

10-minute break

Enablers to accessing support

(10 mins)

We've discussed the challenges people with chronic pain might face in accessing support. Now I'd like you to consider the other side – what makes it easier for people to access support? What has helped you or would help you?

What should services prioritise in their care and support offer?

Prompts if not raised by group:

- *Choice*
- *Speed*
- *Accessibility / proximity*
- *Communication between services*
- *Feeling that you are being listened to and understood*
- *What qualities, knowledge and skills should practitioners have?*
 - *Note for facilitator - Break down whether responses relate to primary care, secondary care or third sector*

Person-centred care

(25 mins)

Next, we'll talk about the idea of 'person-centred care'. Is this a term that people are familiar with? Don't worry if not, I'll talk you through what it means.

Person-centred care

Person-centred care is a practice by which healthcare professionals and services support people to develop the knowledge and confidence to make informed decisions and be involved in their own health and care.

Care and support should be personalised based on the things that are important to the person and help them reach their goals.

Here is a short animation produced by the Nursing and Midwifery Council which explains what we mean by person-centred care, giving some examples of how it works in practice.

<https://www.nmc.org.uk/standards/code/code-in-action/person-centred-care/>

Note for facilitator – important to stop video at 2:50, before section on ‘end of life care’

Does this reflect your experiences of support?

An element of person-centred care is that NHS or healthcare staff take the time to get to know more about you and your circumstances.

To do this, they might have a ‘What matters to you?’ conversation with you. This is a discussion with a medical professional where you are asked about what you need and want in regard to support and care, and what would help you to ‘live well’. and do the things that you would normally do that matter to you.

- *Has anyone got experience of this type of conversation?*
- *Is this something you think is important?*
- *Where and when would you want to do this? (face to face, on the phone, video call)*
- *What could practitioners do to support you and make it easier to take part in this conversation?*

Another element of person-centred care is that all medicines, treatments or advice and options to help you improve your health, are explained well in a way that makes sense to you, and you get the chance to ask questions after.

How do you feel about this?

Prompts if not raised by group:

- *Has this been your experience in the past?*
- *Is this something that is important to you?*
- *What information should be provided?*
- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

Person-centred care also means that patients are involved in decisions about their own health care. Is this important to you?

Prompts if not raised by group:

- *What would help you to participate in shared decision-making conversations?*
- *When and where should these conversations take place?*
- *What resources and information should be provided?*

- *How can practitioners ensure that the information is accessible and understandable to people with chronic pain?*

What would you want someone who is providing care or support to understand about living with chronic pain? What advice would you give them?

Close

(5 min)

- Thank everyone for their participation and contribution
- Remind the group they can email us with any further thoughts if they wish
- Explain we will send £50 as a thank you
- Check everyone is happy to remain involved in the next discussion and confirm we will be in touch soon

FOI - 202300342230 – document 20

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 25 August 2022 10:13
To: REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @gov.scot>; REDACTED gov.scot>; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk>
Subject: Re: Chronic pain - weekly progress update

Dear REDACTED, REDACTED and REDACTED,

Here is our weekly email update: **the project is ON SCHEDULE**

Since our last update, we have:

- Successfully engaged with the Lived Experience Panel, through three discussions and two 1:1 telephone interviews.
- These sessions have gone well - we were pleased with the extent of their engagement and how constructive and open panel members were in sharing their experiences and preferences. We were able to cover all discussion themes and useful learning is emerging
- Transcriptions are being finalised and as soon as that is complete we will enter the qualitative data into an analysis framework

Next week we will:

- Complete the analysis
- Prepare and submit the draft report on emerging findings

Actions/Questions for SG:

- Nothing outstanding at the moment

Don't hesitate to let me know if you have any questions.

Best wishes

Lorraine

FOI - 202300342230 – document 21

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 01 September 2022 10:46
To: REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @gov.scot>; REDACTED gov.scot>; REDACTED @gov.scot>; REDACTED@thelinesbetween.co.uk>
Subject: Re: Chronic pain - weekly progress update

Dear REDACTED, REDACTED and REDACTED,

Here is our weekly email update: **the project is ON SCHEDULE**

Since our last update, we have:

- Made arrangements with the Lived Experience Panel for the second round of discussions, in which we will establish priorities/consensus. These are scheduled for the week beginning the 12th of September.
- Worked on the analysis of the first engagement and emerging findings report - this will be with you tomorrow. It is structured around
 - Findings
 - Experiences of support
 - Organisations and services engaged with
 - Impact of chronic pain on life
 - What does good effective support look like
 - Person-centred care
 - Further research
 - Enablers
 - Barriers
 - Next steps
 - Summary of the second set of engagements with the Pain Panel (week beginning 12th September)
 - Summary of the report on learning from Project 1 (due end of September)
 - Overview of the proposed process for Project 2 (Jan - Mar 2023)

Next week we will:

- Prepare for the second engagement with panel members and respond to any feedback on the emerging findings report

Actions/Questions for SG:

- From our perspective, this afternoon's catch-up this afternoon is not needed - a more helpful discussion can take place once you have had sight of the emerging findings

report. I propose to cancel the meeting - (but I will hold the time and reinstate the invite if there is anything specific you would like to discuss).

Best wishes

Lorraine

FOI - 202300342230 – document 22

From: REDACTED@gov.scot>

Sent: Thursday, 01 September 2022 17:24

To: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>; REDACTED@thelinesbetween.co.uk>; REDACTED@gov.scot>; REDACTED@gov.scot>

Subject: Pain User needs assessment

Hi Lorraine,

Please find attached two documents for your perusal.

The SBAR gives the background and there is a separate draft User Research Brief. We have shared both with NHS24 for them to refine the User Research Brief and we should have their feedback by next week's meeting. The documents are in draft and give you an indication of what we are thinking so not for action but just really to kick off a discussion at the moment.

There are Short Life Working Group meetings scheduled for Action A which you may wish to consider if it would be beneficial for someone from TLB to attend.

Monday 3rd October 2022 (pm)
Monday 7th November 2022 (pm)
Monday 5th December 2022 (pm)
Monday 16th January 2023 (pm)

If you want to ask questions or seek clarification before the meeting on the 8th please just send them over.

Many thanks

REDACTED

Policy Manager – Chronic Pain and Endometriosis

Clinical Priorities

Planning and Quality Division

FOI - 202300342230 – document 22a

<h2>Situation</h2>	<p>A user needs assessment is necessary to inform and shape ongoing implementation of the Framework for Pain Management Service Delivery. This will look at the existing national resource on NHS Inform and also explore what additional resources are required to meet the information needs of people with chronic pain.</p>
<h2>Background</h2>	<p>The Scottish Government has developed a new Framework for Pain Management Service Delivery – Implementation Plan in partnership with people with chronic pain, clinical, research, third-sector communities and other key stakeholders.</p> <p>One of the Commitments in the Plan is to empower people with chronic pain to understand their condition and better manage its impact on their physical and mental wellbeing. This includes improving the quality and consistency of information on chronic pain and self-management making it more easily accessible.</p>
<h2>Assessment</h2>	<p>We have contracted The Lines Between to two phases (projects) of work using the membership of the Pain Panel for Lived Experience. This panel consist of 15 – 22 people who have been recruited using a strict criteria to ensure representation of seldom heard groups and a range of voices from the pain population.</p> <p>NHS24 have expertise and experience to ensure that outputs from lived experience engagement are suitable to inform NHS Inform content.</p> <p>REDACTED (User Research Manager at NHS24) will provide support to advise and support development of user materials (i.e. discussion guides, question sets etc.) and delivery (e.g. facilitation) of activity with the Pain Panel as appropriate.</p> <p>Support will also be provided as appropriate by a Short Life Working</p>

	<p>Group for Aim A (Person Centred Care) which is being established in order to oversee delivery of this part of the Implementation Plan.</p> <p>Current dates for Aim A SLWG: Monday 3rd October 2022 (pm) Monday 7th November 2022 (pm) Monday 5th December 2022 (pm) Monday 16th January 2023 (pm) Monday 27th February 2022 (pm)</p>
Recommendation	<p>We use phase 2 (project) of the Lines Between contract, with support from NHS24 and the Aim A SLWG to carry out user research to</p> <ul style="list-style-type: none">• understand the information needs of the diverse groups living with chronic pain in Scotland;• produce recommendations to improve and commission new information or resources for people with chronic pain on NHS Inform;• produce recommendations for information or resources to be delivered via other channels e.g. off-line content; locally available content etc.

Annex A

User Research

User research helps teams learn about users and create services/resources that meet their needs. Without it, you won't know what problems you're trying to solve, what to design or if the service/resource you create will work well for users.

It is important understand your users, to deliver services/resources that meet user needs. You have to understand:

- who your likely users are
- what they're trying to do
- how they're trying to do it now
- how their life or work influences what they do and how
- how they use and experience existing services/resources

The better you understand your users, the more likely you are to design and build a service/resource that works well for them.

Learning about users and their needs

[Learning about users and their needs - Service Manual - GOV.UK \(www.gov.uk\)](https://www.gov.uk/service-manual/user-research/learning-about-users-and-their-needs)

Discovery research

NHS24 recommend that discovery research be carried out to better understand the needs of the intended user of Chronic Pain information in Scotland. To achieve this they have outlined the activities that should be undertaken.

Discovery research, including:

- Desk research of existing insight evidence
- Focus groups and interviews of target audience
- Analysis of insight to inform design and development
- User Needs Identified and shared with Design Team ((this must be in a suitable format for NHS24 Design Team)

Annex B

Outcomes:

- Reduced impact of chronic pain in Scotland by ensuring more timely and appropriate population-level access to information, self-management support and local services.
- Reduced healthcare service utilisation through increased prevention and earlier intervention for chronic pain.
- Increased knowledge and utilisation of local healthcare pathways and support for pain management.
- Increased awareness and acceptance of self-management and/ or community-based interventions and support ('social prescribing').

Expected benefits:

- Increased utilisation of high-quality, trusted information e.g. NHS Inform, third-sector and local NHS service web-pages (page hits).
- Reduced NHS 111 presentation for chronic pain and more effective onward triage and signposting to resources (service data).
- Increased population knowledge and recognition of pain, chronic pain, its impact and self-management (Scottish Health Survey).
- Increased patient satisfaction with NHS pain management support and services (Scottish Health and Care Experience Survey).
- Reduced health inequalities for chronic pain (Scottish Health Survey).

FOI - 202300342230 – document 22b

Policy Area:	Brief:
Clinical Priorities: Pain Management	Pain Management User Testing
Date:	Brief Author(s):
1 September 2022	REDACTED, REDACTED

1. Policy Background

The Policy Background for this brief has been previously supplied as part of the Invitation to Tender. Key policy document for reference is [Framework for Pain Management Service Delivery – Implementation Plan](#).

2. Research Background

The Lines Between have recently conducted insight gathering with a range of people with lived experience of chronic pain which will debrief shortly. This includes questions on enablers and barriers in terms of accessing support and treatment for chronic pain. The debrief for this research will form part of the background for this project.

A key outcome of the implementation plan is the provision of useful information for people with chronic pain. The location for this is at [Chronic pain - Illnesses and conditions | NHS inform](#) and includes a self-help guide.

User research is now needed to inform the development of this resource on NHS Inform to better meet users' needs in line with the actions in the implementation plan.

3. Research Objectives

Based on the overriding objectives above, specific objectives for the research are as follows:

For all audiences (see below):

- To understand more about their information needs on management of chronic pain
 - Critical points/triggers
 - Stages
 - Themes/ topics
- To establish who the key influencers are and at which points, and what the main sources of information are and at which points
- To establish how users currently meet their information needs regarding chronic pain – both online (websites, social, apps – and which device/s use for these) and offline (e.g. conversations, literature – e.g. leaflets) - what is the role of each?
- To understand what works about their current solution/s – and what does not - in terms of content, format (e.g. text vs video) and authority
- To understand nature of online content that has best met their needs in relation to chronic pain or health generally – form, content, author (e.g. 'expert' vs peer-to-peer) - and platform (e.g. social vs website)
- To understand how information is used – e.g. behaviour change – do they do anything different as a result
- To establish how well the current content and format of information on chronic pain on NHS inform does or does not meet a range of user needs in relation to chronic pain. Does it motivate them to do anything differently or find out more?

4. Research Methodology

We envisage a qualitative approach but we are looking for your recommendations in terms of exact qualitative methods employed to answer the objectives with the audiences highlighted.

Approaches for user testing previously commissioned by Scottish Government usually involve IDI (In Depth Interviews) rather than focus groups and taken an ethnographic approach using users' own devices usually employed for information-seeking tasks like this.

5. Respondent Specification

We are interested in using the Pain Management Panel for this exercise, who have already been recruited to the specifications of interest for this project. This includes people with high impact chronic pain, low impact chronic pain, seldom heard voices and both rural and urban geographies.

6. Output

We require a verbal charted presentation of the findings that delivers insights and makes clear the implications of these for website design and content.

Within this we are looking for specific sections on:

- 1) User sub-groups where applicable (e.g. high impact vs low impact pain)
- 2) Seldom heard groups

Outputs should include verbatim quotes to illustrate key points and recommendations for optimisations to the content on NHS Inform (re: format; content, navigation).

Presentations should be prepared in PowerPoint and delivered either online or hybrid (face to face in Edinburgh with virtual participation via Teams)

7. Timings

Initial outline timings envisaged are shown below. Please provide a detailed timetable in your proposal.

Action	By whom?	When?
Research brief issued	Scottish Government (SG)	Dates to be agreed
Proposal provided	TLB	Dates to be agreed
Proposal Sign Off	SG	Dates to be agreed
Recruitment/fieldwork	TLB	Dates to be agreed
Debrief	All	Dates to be agreed

We appreciate that timings may be restricted by school holidays etc and appreciate your input on this.

8. Budget

Please provide a quote for this work, which is included as part of the overall budget outlined in the initial Invitation to Tender

FOI - 202300342230 – document 23

From: REDACTED @thelinesbetween.co.uk>
Sent: Friday, 02 September 2022 14:56
To: REDACTED @gov.scot>; REDACTED@gov.scot>; REDACTED gov.scot>
Cc: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>; REDACTED @thelinesbetween.co.uk>
Subject: Chronic pain panel: Emerging findings report

Hi REDACTED, REDACTED and REDACTED,

Please find attached our emerging findings report based on our first wave of consultation with the panel.

We look forward to hearing your thoughts.

Have a nice weekend,

REDACTED

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REDACTED | Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
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FOI - 202300342230 – document 23a

Contact: REDACTED@thelinesbetween.co.uk

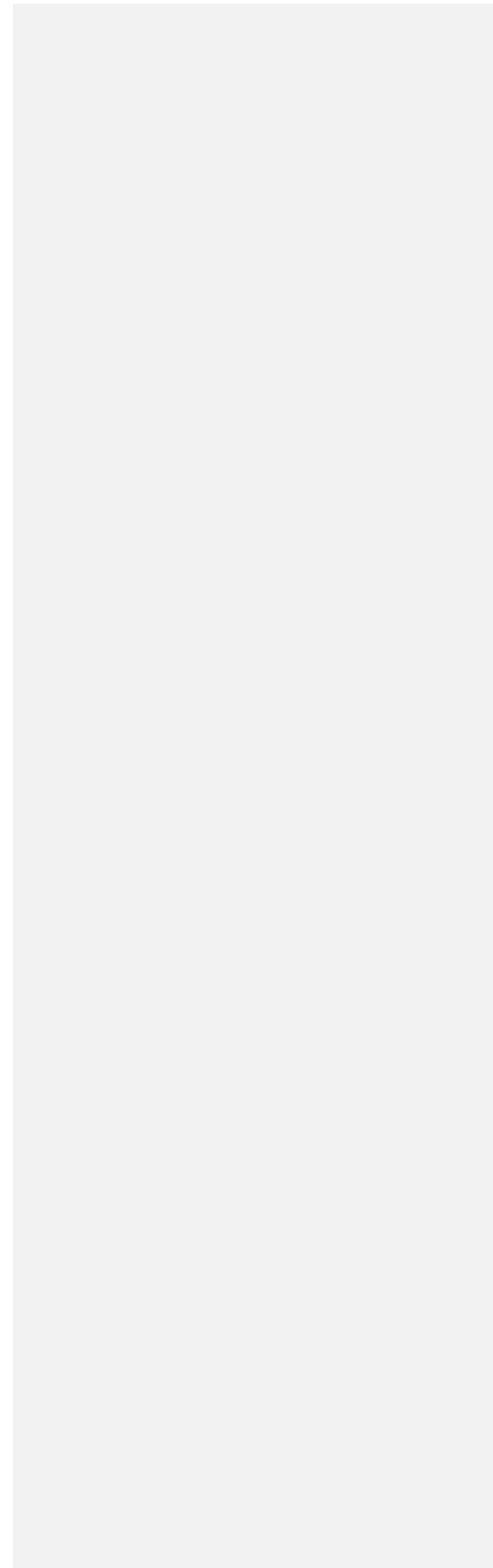
Chronic Pain Lived Experience Panel

Emerging findings report

Prepared for:

© The Lines Between September 2022 1

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2. Emerging findings.....	3
3. Next steps	13 2



1. Introduction

This report presents analysis of initial discussions with the Chronic Pain Lived Experience Panel (Pain Panel) in August 2022. The work was undertaken by The Lines Between, who were appointed to recruit and engage with members of the Pain Panel to inform the development of the Scottish Government (SG) Pain Management Framework and Implementation Plan¹. Engagement with the Pain Panel is being conducted through an approach known as the Delphi methodology. This is a structured process that uses a series of repeated rounds to gather information from a panel of experts in a complex area. It is an approach rather than a fixed method and is adapted to meet the research needs². In general, there are two or three meetings of experts on a topic. The Delphi first meeting involves an open discussion around a range of key themes which are summarised. The second, and any subsequent meetings, consists of presenting the findings to the group and asking them to reach a consensus or prioritise within the key themes.

In the first engagement session, 16 Pain Panel members shared their experiences with chronic pain services, and discussed enablers and barriers to treatment and their views on person-centred care. Participants were given choice in participation methods and these engagements took the form of three small group discussions and two one-to-one telephone interviews. Recruitment of the Pain Panel sought diversity in participants' experiences, circumstances, and characteristics. Diversity across the 16 people who participated in the first engagement session spanned:

Gender: (9 female, 7 male)

Age: (3 x 18-30, 5 x 31-54, 8 x 55+)

Location: (4 x Central Scotland, 7x City, 3 x Rural, 2 x Remote Rural (Shetland & Western Isles))

Socio-economic status: (8 x SEG B-C1, 8x C2DE)

Impact of pain: (3 x no impact, 7 x little impact, 6 x high impact)

Ethnicity: (13 x White British, 2 x Mixed or Multiple Ethnic Groups 1 x Asian)

This report summarises the discussion with the group in the first phase of the Delphi process. The second phase, which will complete the process, will take place in the week beginning 12th September.

¹ <https://www.gov.scot/publications/framework-pain-management-service-delivery-implementation-plan/>

² H. A. Linstone and M. Turoff, "Introduction," in *The Delphi Method Techniques and Applications*, H. A. Linstone and M. Turoff, Eds., pp. 3–12, Addison-Wesley Publishing Company, Reading, Mass, USA, 1975. 3

2. Emerging findings

2.1. Seven overarching themes emerged in the analysis of the first wave of discussions with members of the Pain Panel:

Experiences of support and the range of organisations and services they have engaged with

Impact of chronic pain on life

What good, effective support looks like

Barriers to treatment

Enablers to treatment

Views on the person-centred care approach

Reflections on research into chronic pain

2.2. This chapter presents a summary of the key discussion points under each theme.

Experiences of Support

2.3. Panel members described different aspects of support for living with chronic pain. In these conversations, they reflected on experiences with health services, practical, financial and emotional support, and the overlap between different needs. The importance of maintaining control, independent living and self-agency was raised by panel members, and many described challenging experiences during the pandemic. Some shared specific positive or negative treatment and support experiences they felt policy makers could learn from.

2.4. Details of the specific sources of support accessed by panel members is provided at Table 1.

Table 1: Support accessed by panel members	Examples of services/treatments accessed
Type of support	GP
Medical services provided by NHS	Practice Nurse
	Pain management clinic
	Diabetes clinic
	Multiple Sclerosis (MS) clinic
	Podiatrist
	Physiotherapy
	Hyperbaric oxygen therapy

2.5. Key themes in the discussion of support and examples are presented below:

Experiences with health services

2.6. Engagement with GPs, physiotherapists, hospitals and pain clinics were frequently mentioned in the discussion of experiences of support. GPs were described as a key source of contact; in some cases, GPs were the only health care provider a panel member had engaged with. For others, GPs were a key route to referrals to a range of other services, including alternative therapy sources.

2.7. Panel members described different frequencies of support from health services – some are in regular contact with health providers, and others access services intermittently.

Sources of health support also vary; some use a combination of services provided through the NHS and privately funded therapies.

Well, as far as I'm concerned, I just deal with my GP. I haven't been referred on to anybody else. That's as much support as I have had I'm trying various things like TENS machines. I've paid for loads of treatments like Bowen, KCR, massage everything under the sun.

Practical support

2.8. Practical support was often mentioned by panel members, including the blue badge scheme, mobility aids and adaptations. During these conversations several panel members highlighted the challenge of travelling to appointments, linked to pain, exhaustion and lack of mobility, and stressed how valuable different forms of practical support had been to them.

Financial support

2.9. A small number mentioned the value of welfare benefits as a valued source of financial support; one noted that their initial application for PIP had been rejected and was only approved with support from their MP. This person had also received financial support by MacMillan to fund a cleaner, because their mobility issues affected the extent of what they were able to do at home.

Emotional support

2.10. Some panel members talked about experiences of accessing mental health treatment from health services, including talking therapies and medication to deal with anxiety and depression. In these conversations, others said while they had no experience of such support, they would have valued it.

2.11. The importance of social and peer support for mental health was also highlighted by panel members; some described the importance of care from their partner or family members; others mentioned involvement with forums specifically for people with chronic pain.

Obviously the more you're down in the dumps about things the sorer you feel ... I'm quite lucky that my family is all wound about me and I find that that helps keep me going because if I'm gonna be sitting down in the dumps and in one of them comes in with the kids or whatever, you automatically perk up a wee bit before you realise the pain is not away but it's not as severe.

Experiences with peers differed – while some had positive engagements with peer groups, a panel member who was recently diagnosed with chronic pain found the encounter upsetting. They explained their aspirations and expectations about how to manage pain were different from those who attended the peer session; some peers in the group were self-managing pain through cannabis and this panel member did not want to engage in illicit substance use.

Maintaining control, independent living and agency

2.13. An ongoing desire to maintain independence was mentioned by some panel members. Strands of discussion on this varied; some focused on their physical ability to do things and organise their lives; a few talked about wanting a sense of agency and control over their medication and health services, noting their own research into effective treatments and therapies.

I'm quite independent and I keep trying to be because if I don't then I've given up, you know, that's when bad things start happening to you. I want to be able to continue to work for a long time. I'm in complete denial about what's wrong with me.

Chronic pain during the pandemic

2.14. Panel members often reflected on the pandemic's impact on access to treatment. For example, some who had previously received treatments in hospital or clinics now accessed support from the GP; a few praised the introduction of remote access to healthcare services which they felt was a better use of time and resources.

2.15. One older person said that they had not been physically seen by a healthcare practitioner since the pandemic began; a few highlighted that capacity at their GP surgery had become so stretched that they were unable to get appointments; as a result, one person had changed GPs. Others highlighted that access to some therapies such as yoga and physio had stopped during the pandemic, noting the ongoing backlog in waiting lists to get access again.

If there was something wrong with you, either email you or they will, you know, where you can send pictures they have WhatsApp. That's the kind of facilities that they should have.

I needed, desperately needed contact with somebody but I couldn't, I couldn't even go to the surgery. It was so difficult to get an appointment.

Specific positive or negative treatment experiences

2.16. Panel members were asked about specific positive or negative experiences they felt could be learned from. Discussion of positive experiences typically revolved around the attitude and approach of healthcare practitioners; people who listened, available when you needed them, and keen to bring about change and find solutions that reflected their individual circumstances. Examples include:

The significant contribution of a new consultant who reviewed her medical history and investigated the cause of her pain. He identified the issue and arranged surgery which resolved her condition; until that point she had spent more than two decades using pain medication to live with the pain.

- Experiences of pain management offered by a university which included peer support, yoga sessions, alternative therapies and direct access to a clinician for students living with chronic pain
- A doctor who offered flexible ways to engage with their surgery asked their patients to complete a questionnaire to establish if patients preferred contact in person, or by email, telephone or video conferencing.
- Health care practitioners who take an interest in people and don't make them feel rushed or that they are wasting time.
- 2.17. Specific negative experiences centred on inaccessible services or services that were not appropriate for a person's condition or treatment history. Examples include:
 - One person described their referral to a pain clinic as a 'waste of time' feeling that the service offered only common-sense solutions that were patronising for a person who had lived with a pain condition for a long time.
- Long waiting lists or cancellation of appointments they had waited a long time for.
- Some described practitioners who they perceived to be patronising or disinterested.

Impact of chronic pain on life

2.18. The negative impacts of chronic pain was described by some panel members, including: loss of active lifestyle; disruption to life and plans; loss of income and impediments to employment and volunteering activity; sleeping difficulties sleeping; strong reactions to medications such as feeling dazed, sluggish and sleepy; lack of ability to concentrate; and mental health struggles.

2.19. Some reported a loss of independence, needing help with daily tasks like getting dressed and opening jars; in this discussion, a few mentioned feelings of shame and embarrassment.

2.20. Frustration and a lack of autonomy and feeling they had to go through hoops was also mentioned by some panel members. Examples including being told they needed to meet certain eligibility criteria or try different medications before they could move onto the support they most wanted.

The person was like you can't get referred to the pain clinic unless you've tried various different medications for your back. I've only ever been on amitriptyline and have had my dose increased and I said I'm not prepared, they wanted me to go onto gabapentin. And just what I dread I didn't want to go on it. Because of what my work is I've got to drive and be with it.

What does good, effective support look like?

2.21. Swift access to medical appointments was raised as a priority by several members of the panel. A few suggested that being able to contact their GP by email could cut down on the delays they face when calling their local surgery.

2.22. Access to chronic pain specialists with in-depth training and knowledge about chronic pain conditions and treatments than their GP might have was another important element of good, effective support raised by the panel.

It feels like there's enough people with chronic pain to warrant a specialist section of the NHS just for chronic pain. So that if you're diagnosed with chronic pain long term, you would have, not just your GP, but the chronic pain specialist, who you go to because they'll have a better understanding of your condition and which route to go down; whether it's medication, or mental or physical help. That's what I would like to see.

Some said that in an ideal world, support for chronic pain would be delivered in a joined up, holistic approach, so that service users had one point of contact for financial, physical and emotional support. Access to free counselling, a range of different physiotherapies (e.g. Bowen therapy) and equipment (e.g. TENS machines) through the NHS was noted as a priority for some.

2.24. Others mentioned that home visits from medical professionals and prescription deliveries would be welcome. However, there was recognition that limited NHS resources would be a barrier to this.

2.25. A few stressed the importance of access to socialising opportunities for people experiencing chronic pain, noting that they often face barriers to an active social life such as mobility problems and poor mental health, which increases their risk of social isolation. The panel suggested that people living with chronic pain should be referred to local peer support groups, and transport provided in cases where individuals are unable to organise this themselves.

Send them a letter and say, 'we've got this little group going'. If they could send that to people that with chronic pain...it would get them out of the house for a little while. Even if they couldn't make their own way there, get an ambulance or share a pickup for a few of them. Take them there and let them get out a bit. Instead of sitting in the house. We could do a wee bit more to make people aware of what's happening and that there are things for them. So they don't have to be on their own.

Person centred care

2.26. Panel members had mixed reactions to the short video and explanation of person-centred care. Some felt that this approach was reflected in their experiences of accessing support for chronic pain, noting that some of the doctors and nurses they had interacted with spent time getting to know them and more about their lives and personal circumstances.

Yes, these things have happened to me and it's good. It shows that they care. ...It's showing an interest. They're not just there to see what you've gone in for that day, they are looking back and asking you how you feel then and is it still the same or is it any better, and it just helps you.

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I recognise that, not from my normal GP, but the younger ones that come in, they give you the time. They ask and stuff as if it's a bit more person-centered on the bigger picture.

2.27. A few members of the panel had experience of being involved in decisions about their health and care plan. For example, one was given a list of different medication for MS with information on each and asked for the input in selecting one.

2.28. However, others did not feel that their experiences of support aligned with person-centred care, and argued that the approach, while aspirational, seems unrealistic given the time and caseload demands of health care professionals.

Yeah, that's a pipe dream compared to the experience I've had the last couple times I've been in hospital.

They're looking at you as a number; they want you in and out the door as quickly as possible. They don't have the time to sit and do this just now, because they don't have the staff, they can't recruit the staff. It's what we should be getting, but it's not what we will get.

It's like the opposite. If you showed GPs or hospitals that they would laugh you out the room. They haven't got the resources to do the basics, nevermind whatever that is.

2.29. There were mixed experiences of how treatment plans had been explained to the panel in the past. Some shared instances where they felt well-informed, and others described experiences of being left with little to no information.

2.30. A few suggested that it would be helpful if they were to receive a short letter or email summarising what had been discussed after each of their medical appointments, and this would make them feel more well-informed. Consistency (in terms of seeing the same health care professional at each appointment) and kindness were also noted as important aspects of person-centred care by the panel.

Enablers

2.31. The main enabler to accessing services discussed by the panel was the confidence and ability to advocate for yourself when seeking support for chronic pain. Some described having to repeatedly request referrals, further testing and new treatments from medical professionals.

That's how I found out about the pain clinic – I had to kind of fight a battle to get that referral done.

I think if you don't fight for it they just kind of leave you to it. If you don't say 'I want this, this and this' they'll just go, 'alright we can get away with giving them this' and then just kind of brush it off.

I had to go back to the doctors about three times to see if I could get physio.

2.32. One panel member commented that free prescriptions are an enabler in that they remove affordability barriers for people with chronic pain when accessing medication.

2.33. Across discussions, it appeared that panel members who were being supported by progressive health care practitioners felt they were receiving better quality care than their peers; that this care was more flexible and appropriate to their needs.

Barriers

2.34. The panel shared experiences of various barriers to accessing support for chronic pain in the past. These included limited NHS resources, concerns over a reliance on painkillers masking the root cause of pain, physical and emotional barriers, lack of empathy and understanding from healthcare staff, lack of awareness of services and barriers linked to identity/protected characteristics.

Limited NHS capacity/resources

2.35. Several panel members noted barriers related to NHS capacity and resources. They described struggling to get an appointment with their doctor and facing lengthy waiting times to access health services.

GPs seem to be so stressed right now, you can hardly even get an appointment to see them. So it's very frustrating, really, when you are in an awful lot of pain. There's nobody there to help you.

I've got stage four endometriosis, and the waiting list for anything related to endometriosis or anything like that is horrific, absolutely horrific. So I had to wait for the first Stobhill appointment that was four and a half months it was, for that one to then be cancelled.

I was on a massive waiting list to be seen at the chronic pain clinic and that took six months to get a phone consultation.

2.36. A few commented on the limited services and medications available on the NHS compared with private healthcare, and one noted difficulty securing medication due to supply shortages.

We are hitting another big problem now. I'm struggling a lot of times to get the medication... I've got to phone round chemists to see who's got what I'm looking for in stock because there's such a shortage of medication out there now.

Concerns over medical reliance on painkillers and lack of focus on root cause of pain

2.37. Some panel members described experiences of presenting at health services with chronic pain, and being dismissed with painkillers with little effort to explore or identify the root cause of the pain. In some cases this linked to the length of time that a person had been living with a chronic pain condition – a feeling that health care services were not looking for a solution they were expected to manage, through a reliance on painkillers.

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It shouldn't be a case of, 'oh well just keep taking the tablets.' I feel that the hospital people could investigate... look a bit further and see if there's anything else that can be done for them, because if you've got chronic pain, you would like to get investigated.

Mine was really severe migraines and then the sciatica I got I could hardly walk. And they just gave me painkillers and said, 'Oh, go away.'

2.38. The over-reliance on pain medication triggered concern with the panel, many of whom were reluctant to take strong painkillers for long spells of time; fearing addiction, loss of cognition or other side effects interfering with the demands of their lives, e.g. work and tasks like driving. Some members of the panel lost confidence in health services as a result.

If you're taking all these heavy painkillers as well then it has an effect on your day-to-day life because then you are sluggish you don't feel as if you want to get up and do anything because you are medicated.

I was 150 milligram Amitriptyline which is absolutely huge, so I was a total zombie and I thought I just can't live like this...I'd lost confidence in the GPs, so I didn't go back and ask these kind of questions."

"I've only ever been on Amitriptyline and have had my dose increased and they wanted me to go onto Gabapentin. And I just dreaded it. I didn't want to go on it. Because part of my work is I've got to drive and be with it."

“Phoning the GP, it was basically, ‘do you want a stronger form of co-codamol?’ And I’m like no, I don’t want to be on it, it’s highly addictive and I only take that when I am climbing the wall with pain.”

Physical barriers

2.39. Mobility issues associated with chronic pain made it difficult for some to access in person services.

Another barrier would be - depending on where your surgery is - trying to get there. If you don’t have a car or transport, it’s quite awkward, especially if they have to walk with a stick or if their mobility is not good.

2.40. Those in rural areas noted distance to services along with poor public transport infrastructure as barriers to accessing support.

I did try and join a support group...but I’m 17 miles here for a pint of milk, in the middle of nowhere, you know, in the hills. If we want to go to the meetings, I’ve got to go to 100 miles to Edinburgh... I certainly can’t afford to travel 100 miles to go to a support group.

Emotional barriers

2.41. A few said that spells of poor mental health affected their motivation to access support.
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You’ve maybe just got to a stage where you just resign yourself to, this is me, you know? I’ll try as hard as I can not to let it get any worse but I genuinely don’t believe I can get any better.

Lack of empathy and understanding from medical practitioners

2.42. A few panel members felt as though their pain hadn’t always been taken seriously by medical practitioners and said they had often been dismissed or made to feel as though they were exaggerating their pain.

I think, at the very beginning that you are sometimes made to feel like a hypochondriac.

Lack of awareness of services

2.43. Some pointed to a lack of awareness of services as the reason they had not accessed any support. A few said they were unaware of any support outwith their GP, and a small number said they had never heard of the pain clinic.

Barriers related to identity/protected characteristics

2.44. While the topic was raised in all discussions, very few panel members had direct experience of any barriers in accessing support which related directly to their personal identity or protected characteristics.

2.45. One panel member shared how he felt that as a man, he had been raised to ‘grin and bear’ his pain. One of the younger members of the panel said that he felt his chronic pain wasn’t taken as seriously as that of an older person, noting his doctors assumed that he had strained his back through exercise as opposed to something more long term and in need of deeper investigation.

Thoughts on research into chronic pain

2.46. One participant called for more investment into research about chronic pain conditions.

There needs to be more research into certain types of illnesses and chronic pain... they don’t know the answers, they don’t know the best ways to deal with them. There needs to be more

research into why people are experiencing these pains and what can be done to remedy it us and help people live their day to day lives.

2.47. Some panel members expressed appreciation at being a part of the lived experience panel and having the opportunity to feed into the formation of the chronic pain framework and implementation plan.

I think it's great that they're doing this. Hopefully, some good will come out of it.

Thank you for caring to ask.

3. Next steps

Introduction

3.1. This chapter describes:

the next steps in the panel engagement which will complete project one.

features of the second project, which will also involve two sets of engagements.

Project one: second engagement with the pain panel

3.2. The aim of the second engagements in project one is to prioritise the issues in each of the topics which were explored in the first round. These initial topics were based on the chronic pain framework.³ We will do this using the Delphi method; a structured process that uses a repeated rounds to gather information from a panel of experts in a complex area. It is an approach rather than a fixed method and therefore is adapted to meet the needs of the research.

³ Chronic pain service delivery-draft framework delivery

<https://www.gov.scot/publications/draft-framework-chronic-pain-service-delivery/pages/7/>
[accessed 01/09/22]

Features of second engagement

- 1. Participants will meet online in the same group or interview as in the first engagement.**
- 2. They will be presented with a topic and the themes that emerged from the first meeting.**
- 3. Some discussion will take place to ensure shared understanding and that there is nothing missing.**
- 4. Participants will individually rate these themes in order of priority.**
- 5. This will be repeated for each of the four topics.**
- 6. Ratings will be combined across the groups to create a total score.**
- 7. Each topic will then have a list of combined priorities for the group.**

3.3. The Delphi process typically involves two or three meetings of experts in a topic. The first meeting, which has already taken place involves an open discussion around a range of key topics, which are then summarised as presented in Chapter 2. The second, and any subsequent meetings, involves presenting the summarised findings to the group and asking them either to reach consensus or to prioritise within the key themes.

FOI - 202300342230 – document 24

From: Lorraine Simpson **REDACTED** @thelinesbetween.co.uk>
Sent: Thursday, 08 September 2022 11:06
To: **REDACTED** @thelinesbetween.co.uk>
Cc: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>;
REDACTED @thelinesbetween.co.uk>
Subject: Re: Chronic pain - weekly progress update

Hi All

Looking forward to our catch-up later today. Here is our weekly email update: **the project is ON SCHEDULE**

Since our last update, we have:

- Submitted the emerging findings report
- Received details from **REDACTED** on the planning activities that will take place in the run-up to Project 2.

Next week we will:

- Undertake the second engagement with panel members

Actions/Questions for SG:

- I understand you may have some feedback from NHS24 on the User Resarch briefing to share this afternoon.
- We look forward to receiving your feedback on the emerging findings report. It would be helpful if you could confirm at the meeting if you are happy with the key themes outlined in the report for the consensus work we have planned with the Pain Panel members next week. As a reminder, these are:
 - 1. Support and care people have received and which elements they have found useful.
 - 2. Barriers to accessing support.
 - 3. What has helped people feel more in control of chronic pain.
 - 4. Effective delivery of person-centred care.
- We would like to attend the groups mentioned in **REDACTED** email (3rd Oct 3, 7th November, 5th December and 16th January). Can you send details when they are ready, please.

Best wishes

Lorraine

FOI - 202300342230 – document 25

From: **REDACTED** @thelinesbetween.co.uk>
Sent: Thursday, 15 September 2022 11:33
To: **REDACTED** @thelinesbetween.co.uk>

Cc: REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>;
REDACTED @thelinesbetween.co.uk>
Subject: Re: Chronic pain - weekly progress update

Hi All

Sorry for my unexpected non-appearance at the update meeting last week and thanks for your understanding. [OUT OF SCOPE]

Here is our weekly email update - pleased to report **the project is ON SCHEDULE**

Since our last update, we have:

- Completed the 2nd phase of engagement with the Pain Panel, to identify consensus and priorities

Next week we will:

- Undertake the analysis and work on the updated report, to be submitted w/c 26th September.

Actions/Questions for SG:

- Please let me know when you will be in a position to share feedback on the emerging findings report. We plan to incorporate elements of that report into the full report on Project 1 - so if you require significant changes, just let me know.
- From our perspective, this afternoon's catch-up this afternoon is not needed - we're just beginning the analysis of the second stage of engagement with Pain Panel members and I'm not in a position to share emerging findings from that yet. I propose to cancel the meeting - (but I will hold the time and reinstate the invite if there is anything specific you would like to discuss).

Best wishes

Lorraine

FOI - 202300342230 – document 26

From: Lorraine Simpson REDACTED @thelinesbetween.co.uk>
Sent: Thursday, 15 September 2022 16:51
To: REDACTED @gov.scot>
Cc: REDACTED gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk
Subject: Re: Chronic pain - weekly progress update

Thanks, REDACTED this is very helpful. I'm signing off now for the long weekend, but we will incorporate this feedback when we work on the revised report. Glad the emerging findings filled the gaps you were interested in - we can provide more detail and insight in the next report.

Best wishes

Lorraine

On Thu, Sep 15, 2022 at 4:29 PM <REDACTED@gov.scot> wrote:

Hi Lorraine,

Please see feedback...

The report is very helpful in illustrating the experience of people with low impact pain, who might 'only' have accessed primary care and not specialist pain services. This is a gap we have had in previous insights reports, so extremely useful to have this.

The quotes really help bring the report to life but could you please look at adding brief descriptors for each in regard to the participant - based on recruitment screener eg region; pain impact (low vs high) – e.g.

“body of quote/key verbatim content”

- Highland, Low impact Pain, DE socio-economic group

Can we please show differences between groups where relevant - rural/urban; age; gender; other characteristics – in particular to illustrate the experience of seldom-heard groups, which is a key focus for us (whether on account of e.g. socio-economic group/ SIMD most deprived area, minority ethnic group or disability).

Section 2.16 is especially useful in regard to detailing specific positive and negative experiences. We are keen to learn more about what worked for people (in terms of impact on their pain), so if this section could be expanded somewhat to include that – or perhaps this will be included in the consensus work, key theme 3?

Overall, we agree with the key themes you outline for the consensus work, one small requested addition (in yellow):

1. Support and care people have received and which elements they have found useful.

- 2. Barriers and enablers to accessing support.

- 3. What has helped people feel more in control of chronic pain.
- 4. Effective delivery of person-centred care.

Kindest regards,

REDACTED

Policy Manager – Chronic Pain and Endometriosis

Clinical Priorities

Planning and Quality Division

FOI - 202300342230 – document 27

From: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>

Sent: Thursday, 22 September 2022 10:42

To: **REDACTED** @thelinesbetween.co.uk>

Cc: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>

Subject: Re: Chronic pain - weekly progress update

Hi All

Here is our weekly email update - pleased to report **the project is ON SCHEDULE**

Since our last update, we have:

- Continued work on the draft final report on phase 1. This includes addressing your feedback on the emerging findings report, and undertaking analysis of the results from the consensus work.

Next week we will:

- Submit the updated report.

Actions/Questions for SG:

- I look forward to our meeting later today. In particular, I'm keen to discuss what you are looking for in terms of 'reporting on the learning from Project 1 - opportunities and challenges to consider before proceeding to Phase 2' - as that will help inform our reporting.
- Please send through details of the meeting on 4th October, when you have them. Any steer you can give me at the moment would be helpful for example is it online, or in person?

Best wishes

Lorraine

FOI - 202300342230 – document 28

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 29 September 2022 12:35
To: REDACTED@thelinesbetween.co.uk>
Cc: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>
Subject: Re: Chronic pain - weekly progress update

Hi All

Here is our weekly email update - pleased to report **the project is ON SCHEDULE**

Since our last update, we have:

- Continued work on the draft final report on phase 1. This includes addressing your feedback on the emerging findings report, and undertaking analysis of the results from the consensus work. The report is being finalised this afternoon with final proofs and formatting, and will be submitted tomorrow morning

Next week we will:

- Attend the Pain Management Person Centred Care SLWG on Monday morning
- Respond to any feedback on the draft report

Actions/Questions for SG:

- From our perspective, this afternoon's catch-up this afternoon is not needed - we're still finalising the report, which you will receive tomorrow morning. I propose to cancel the meeting - (but I will hold the time and reinstate the invite if there is anything specific you would like to discuss). Hopefully, you will have time to review it next week and we can discuss it at the meeting on Thursday.

Lorraine

FOI - 202300342230 – document 29

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 06 October 2022 12:04
To: REDACTED@thelinesbetween.co.uk>
Cc: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>

Subject: Re: Chronic pain - weekly progress update

Hi everyone

Here is our weekly email update - pleased to report **the project is ON SCHEDULE**

Since our last update, we have:

- Submitted the draft final report on phase 1.
- Attended the Pain Management Person Centred Care SLWG on Monday morning

Next week we will:

- Respond to any feedback on the draft report

Actions/Questions for SG:

- At this afternoon's catch up I'd be grateful if we could talk about the SLWG meeting, where they outlined a core programme of work which includes TLB doing a user needs assessment in October and November, with a final report in December. I assume this is the user research project we are describing as Project 2 - however, our understanding was that this work is to take place in Jan-March next year. In the meeting papers, TLB was described as having a core role in the SLWG, and this entails a commitment to delivering a work plan between meetings and attending every meeting - I was not aware of this expectation. I said I would seek clarification from you before the next SLWG meeting - be good to discuss this today, or when Sharon returns from leave if she's the best-placed person to talk about it.

Look forward to catching up later today

Lorraine

FOI - 202300342230 – document 30

From: REDACTED @gov.scot>
Sent: Thursday, 06 October 2022 12:13
To: Lorraine Simpson <REDACTED @thelinesbetween.co.uk REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @gov.scot>; REDACTED @gov.scot>
Subject: RE: Chronic pain - weekly progress update

Hi Lorraine

I was just about to email you! Thanks for the update and yes, very happy to discuss the SLWG and expectations around TLBs role and contribution.

On the report, huge thanks to your team for this really impressive piece of work - we really like the format and especially the quotes which are well presented.

See attached our initial comments on this draft which are hopefully helpful. We also have some overarching points that would be useful to get your views on this afternoon when we catch-up, namely:

- We are considering if we might publish this as a resource on the SG website – good to get your thoughts on this
- We think we would require an exec summary to be added also for that purpose

- We think this could also provide some context on existing quant on chronic pain (e.g. existing national survey work) to illustrate how and why we have taken this qual approach – we can provide links to relevant info/research
- The infographics are really useful for us to see but would be good to discuss what might be helpful for publication

Looking forward to catching up, and thanks again for your ongoing great work!

Best
REDACTED

REDACTED Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 30a



FOI - 202300342230
- document 30a - pdf.

FOI - 202300342230 – document 31

From: **REDACTED** @thelinesbetween.co.uk>
Sent: Thursday, 13 October 2022 13:06
To: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Cc: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Subject: Chronic Pain Panel - weekly progress update

Hi everyone,

Lorraine is on annual leave today so I'm providing the update this week. (A heads up that Lorraine is also away next week so it will be the same next Thursday).

The project is ON SCHEDULE

Since our last update, we have:

- Re-drafted the Phase 1 report (attached)
 - As the format has changed, the comments/tracked changes were not copied over, so we have kept a log of them in the attached spreadsheet. The spreadsheet explains how we have responded to each piece of feedback and there are a few actions flagged for SG.

- Attended the Alliance Scotland event

Next week we will:

- Await further feedback on the Phase 1 report, and begin drafting the exec summary once we have this version finalised.

Actions/Questions for SG:

- There are a small number of actions flagged in the attached spreadsheet which we could use a little bit more steer/guidance on

I am happy to go ahead with our weekly update meeting this afternoon, but I would understand if you'd like to wait til next week so you've had a chance to look at the 2nd draft of the report. Just let me know.

Kind regards,

REDACTED

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REDACTED | Senior Researcher
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3 Piershill Place, Edinburgh, EH8 7EH
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www.thelinesbetween.co.uk | @thelinesbetweet

FOI - 202300342230 – document 32

From: **REDACTED**@gov.scot>

Sent: Wednesday, 19 October 2022 16:43

To: **REDACTED** @thelinesbetween.co.uk>; **REDACTED** gov.scot>; **REDACTED**

Cc: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>

Subject: RE: Chronic Pain Panel - weekly progress update

Good Afternoon **REDACTED**,

Thank you for this. I found the attached but I am not sure if this is what you are looking for [20200214-ebcd-evaluation-summary-report-v10.pdf \(ihub.scot\)](#) ([Experience-based Co-design | Healthcare Improvement Scotland - Experience-based Co-design \(ihub.scot\)](#)) regards to references mentioned at row 5 of the excel grid.

REDACTED is not back until next week and **REDACTED** will not be around tomorrow so numbers will be low I therefore suggest we put time in for early next week when people have had a chance to review the updates etc more fully.

I was also wondering if there was an initial draft for the next piece of work on the user needs? And if so is it at the point it can be shared with us?

Kindest regards,

REDACTED
Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 33

From: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Sent: Monday, 24 October 2022 12:26
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Subject: Re: Chronic Pain Panel - weekly progress update

Hi **REDACTED**

We're now getting ready for Project 2 Does this timeline work for you?

- develop and finalise research tools by 10th November
- engage with the panel across in the week beginning 14th November, followed by analysis and reporting
- share draft findings with you on Weds 30th Nov,
- discuss them with you on 1st December,
- then present to the SLWG at the meeting on 5th December.

Re: development of discussion guides, when you sent us information about the User Needs Research, you mentioned that you had shared the draft documents with NHS Inform and were awaiting their feedback - did you get any further feedback from them? If not, then can you confirm we should develop a discussion guide based on the following:

For all audiences (see below):

- To understand more about their information needs on management of chronic pain
 - Critical points/triggers
 - Stages
 - Themes/ topics
- To establish who the key influencers are and at which points, and what the main sources of information are and at which points
- To establish how users currently meet their information needs regarding chronic pain – both online (websites, social, apps – and which device/s use

for these) and offline (e.g. conversations, literature – e.g. leaflets) - what is the role of each?

- To understand what works about their current solution/s – and what does not - in terms of content, format (e.g. text vs video) and authority
- To understand nature of online content that has best met their needs in relation to chronic pain or health generally – form, content, author (e.g. 'expert' vs peer-to-peer) - and platform (e.g. social vs website)
- To understand how information is used – e.g. behaviour change – do they do anything different as a result
- To establish how well the current content and format of information on chronic pain on NHS inform does or does not meet a range of user needs in relation to chronic pain. Does it motivate them to do anything differently or find out more?

I have a few questions about the above -

- can you describe what you want us to explore under "critical points/triggers, stages, and themes/topics" to explore under information needs please - do you want open discussion under these headings or specific issues explored
- what does "establish who the key influencers are" mean? What sorts of insights are you looking for on that point?
- re: existing content about chronic pain on NHS inform - a quick google search under "NHS inform chronic pain" brings up several options (see below)- do you want the panel to review all of these? Anything else? Or just a specific part of the website?

<https://www.nhsinform.scot> › illnesses-and-conditions

[Chronic pain - Illnesses and conditions | NHS inform](#)

Chronic or persistent pain is pain that carries on for longer than 12 weeks despite medication or treatment. Most people get back to normal after pain ...

<https://www.nhsinform.scot> › mental-health › chronic-p...

[Chronic pain self-help guide | NHS inform](#)

Chronic pain self-help guide. Work through a self-help guide that uses cognitive behavioural therapy (CBT) to help you live with chronic pain.

<https://www.nhsinform.scot> › symptom-control › contr...

[Controlling pain | NHS inform](#)

11 Dec 2020 — If you have frequent or constant pain it's important to take pain medication regularly. Each dose of pain medication should be enough to manage ...

<https://www.nhsinform.scot> › scotlands-service-directory

[Yoga for chronic pain - Health and Well-being - NHS inform](#)

6 Dec 2018 — Yoga for chronic pain class every Tuesday at Pollok Civic Real Community room, 3-4pm. Services Offered. Isolation and Loneliness; Sport and ...

Look forward to catching up this week. Please let me know when you have in mind for an early catch up. My diary is packed today but I have some time tomorrow afternoon and on Wednesday morning - failing that we can stick with the scheduled meeting on Thursday.

Best wishes

Lorraine

FOI - 202300342230 – document 34

From: REDACTED@gov.scot>

Sent: Thursday, 27 October 2022 17:07

To: 'Lorraine Simpson' <REDACTED@thelinesbetween.co.uk>

Cc: REDACTED@thelinesbetween.co.uk; REDACTED@gov.scot>; <REDACTED@gov.scot>

Subject: RE: Chronic Pain Panel - weekly progress update

Hi Lorraine

Lovely to see you earlier. Here is the paper as promised. Any further questions or clarification needed just let us know.

thanks

REDACTED

Policy Manager – Chronic Pain and Endometriosis

Clinical Priorities

Planning and Quality Division

FOI - 202300342230 – document 34a

Proposed timeline

What	When
SG and NHS24 to answer TLB queries on proposal	w/c 24 th October
TLB to share draft proposal with SG;	w/c 31 st October
SG to share draft proposal with SLWG A membership for input	w/c 31 st October
TLB, SG and SLWG A to discuss and finalise proposal	SLWG Meeting 7 th November
TLB to develop and finalise research tools	By 10th November
TLB to engage with the panel across in the week beginning 14th November, followed by analysis and reporting	w/c 14 November
TLB share draft findings with SG	30 November
TLB discuss them with SG	1st December
TLB present to SLWGA	5th December

For all audiences (see below):

- To understand more about their information needs on management of chronic pain:
 - Critical points/triggers
 - Stages
 - Themes/ topics
- To establish who the key influencers are and at which points, and what the main sources of information are and at which points
- To establish how users currently meet their information needs regarding chronic pain – both online (websites, social, apps – and which device/s use for these) and offline (e.g. conversations, literature – e.g. leaflets) - what is the role of each?
- To understand what works about their current solution/s – and what does not - in terms of content, format (e.g. text vs video) and authority
- To understand nature of online content that has best met their needs in relation to chronic pain or health generally – form, content, author (e.g. 'expert' vs peer-to-peer) - and platform (e.g. social vs website)
- To understand how information is used – e.g. behaviour change – do they do anything different as a result
- To establish how well the current content and format of information on chronic pain on NHS inform does or does not meet a range of user needs in relation to chronic pain. Does it motivate them to do anything differently or find out more?

Questions from TLB on the above

Query	Response
can you describe what you want us to explore under "critical points/triggers, stages, and themes/topics" to explore under information needs please - do you want open discussion under these	<ul style="list-style-type: none">• Explore when people with chronic pain seek information• Explore what type of content people with chronic pain are looking for• Explore how people with chronic pain access information

<p>headings or specific issues explored</p>	<ul style="list-style-type: none"> • Explore the barriers people with chronic pain experience when seeking information • Explore what outcomes people with chronic pain expect when seeking information
<p>what does "establish who the key influencers are" mean? What sorts of insights are you looking for on that point?</p>	<ul style="list-style-type: none"> • Where do people with chronic pain go for information • What sources and organisations do people with chronic pain trust for advice
<p>re: existing content about chronic pain on NHS inform - a quick google search under "NHS inform chronic pain" brings up several options (see below)- do you want the panel to review all of these? Anything else? Or just a specific part of the website?</p>	<ul style="list-style-type: none"> • We would like the panel to review the following pages/resources on NHS Inform: • Main page: https://www.nhsinform.scot/illnesses-and-conditions/brain-nerve-and-spinal-cord/chronic-pain • Self-help guide: https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/chronic-pain-self-help-guide • Queries with the group on these resources should include: <ul style="list-style-type: none"> ○ Helpfulness of the information and content ○ Ease of use in accessing content ○ Ease of use in reading/ understanding content ○ Exploration of what additional information should be available ○ Exploration of what additional languages, formats (e.g. video content) should be available

<https://www.nhsinform.scot> › illnesses-and-conditions

[Chronic pain - Illnesses and conditions | NHS inform](#)

Chronic or persistent pain is pain that carries on for longer than 12 weeks despite medication or treatment. Most people get back to normal after pain ...

<https://www.nhsinform.scot> › mental-health › chronic-p...

[Chronic pain self-help guide | NHS inform](#)

Chronic pain self-help guide. Work through a self-help guide that uses cognitive behavioural therapy (CBT) to help you live with chronic pain.

<https://www.nhsinform.scot> › symptom-control › contr...

[Controlling pain | NHS inform](#)

11 Dec 2020 — If you have frequent or constant pain it's important to take pain medication regularly. Each dose of pain medication should be enough to manage ...

<https://www.nhsinform.scot> › scotlands-service-directory

[Yoga for chronic pain - Health and Well-being - NHS inform](#)

6 Dec 2018 — Yoga for chronic pain class every Tuesday at Pollok Civic Real Community room, 3-4pm. Services Offered. Isolation and Loneliness; Sport and ...

FOI - 202300342230 – document 35

From: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Sent: Wednesday, 02 November 2022 10:01
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Subject: Re: Chronic Pain Panel - weekly progress update

Dear **REDACTED**

As promised, please find a summary proposal attached which sets out the key features of the user research activity. We are working on Appendix 2 - the draft question schedule and will send that on today or tomorrow.

Re: timetable for the revised report, will have that to you on Monday

Don't hesitate to let me know if you require any changes or clarifications before you share it with the SLWG.

Do you need **REDACTED** to talk through the paper at the meeting on Monday, or will your team be leading on any discussion?

Best wishes

Lorraine

On Mon, Oct 31, 2022 at 3:39 PM <**REDACTED** @gov.scot> wrote:

Hi Lorraine

Hope you had a nice weekend. As discussed last week please see attached the draft report with collated SG comments. Hopefully these are fairly minor and straightforward, but please don't hesitate to get in touch should you have any questions.

We're still aiming to get this published in the coming weeks if at all possible so appreciate your flexibility and apologies again for the delay getting this back to you.

We discussed the approach to the User Research work with the SLWG Chair today, and we're hoping to share the proposal with the group before the meeting next Monday – is that still OK?

Best wishes
REDACTED

REDACTED

Senior
Policy
Manager
– Chronic
Pain

User Research with people who have lived experience of chronic pain

Clinical
Priorities

A summary by The Lines Between for:

FOI -

202300342230 – document 35a

Research Brief

- 1.1. The Scottish Government is undertaking a range of activity with stakeholders to inform the [Framework for Pain Management Service Delivery – Implementation Plan](#).
- 1.2. A key outcome of the implementation plan is the provision of useful information for people with chronic pain. This is found online at [Chronic pain - illnesses and conditions |](#)

[NHS inform](#) and includes a self-help guide.

1.3. User research will inform the development of this resource on NHS Inform, to better meet users' needs in line with the actions in the implementation plan. This user research will generate an understanding of:

- **Information needs and current sources of insight on management of chronic pain:**
 - When people with chronic pain seek information, and what outcomes they expect
 - What type of content people with chronic pain require
 - How people with chronic pain access information
 - Any barriers people with chronic pain experience when seeking information
 - Where people with chronic pain go for information
 - The sources and organisations people with chronic pain trust for advice
 - How users currently meet their information needs regarding chronic pain – both online and offline) - the role of online and offline information sources.
 - What works and does not work about their current solution/s in terms of:
 - content
 - format (text vs video)
 - authority
 - Views on existing online content that has best met their needs in relation to chronic pain or health generally – form, content, author and platform
 - How information is used to inform behaviour change
- **Feedback on NHS Inform:**
 - How well the current content and format of information on chronic pain on NHS inform:
 - meets a range of user needs in relation to chronic pain, and
 - if it motivates them to change behaviours or find out more information.
 - Helpfulness of the information and content
 - Ease of use in accessing content
 - Ease of use in reading/ understanding content
 - What additional information should be available
 - What additional languages, formats (e.g. video content) should be available

1.4. Insights into a range of experiences and opinions will be generated by user research, which can be translated into practical suggestions to enhance information for people with chronic pain.

Our experience and approach

1.5. The Lines Between have extensive experience in recruiting and consulting with vulnerable and seldom heard groups, often exploring sensitive subject areas and life experiences. For example, we have worked with people who are living with chronic pain, who have severe complex and enduring mental illness, experience of gender-based violence, homelessness, drug and alcohol harms, young people with experiences of the care sector, people from areas with high levels of multiple deprivation, people seeking asylum, and people bereaved by suicide.

1.6. We also bring experience of user research. Examples include recent work for NHS GG&C to develop an app for accessing STI home-testing, research with people who do not use libraries to inform the engagement strategy for the National Library of Scotland, and research with young audiences for the BBC Symphony Orchestra. In a former role,

Contact: REDACTED@thelinesbetween.co.uk

Managing Director Lorraine Simpson was lead researcher on a project for NHS Scotland to develop and test patient information leaflets with ESOL learners.

- 1.7. Through our expertise in recruiting and engaging with people lived experience we know how to quickly build trust, work sensitively, adapt any materials given, or research techniques used, to their needs and support them to share their views.
- 1.8. Our team are passionate about effective communication, which includes engagement with people with lived experience to ensure that their views are understood and presented clearly to the Scottish Government and other stakeholders across NHS Health Boards.

Engagement with the lived experience panel

- 1.9. User research workshops will take place online and be facilitated by Managing Director Lorraine Simpson, with support from Senior Researcher REDACTED. Both are highly experienced facilitators who are effective at ensuring all voices are heard and no one dominates.
- 1.10. These workshops are scheduled to take place in the week commencing 14th November. We have already successfully engaged with Chronic Pain panel members to facilitate their input into the development of the Pain Management Treatment Framework Implementation Plan, and will build on this strong foundation for the user research.
- 1.11. The user research sessions will start with a focus on what needs to be achieved and how any disagreement should be handled. We will use the chatbox function to increase participation and feedback channels within the session.

Profile of users with experience of chronic pain

- 1.12. User research will involve a panel of people with experience of chronic pain who have recently taken part in a lived experience engagement exercise. To increase the impact and address inequalities facing people with chronic pain, the Scottish Government (SG) sought to increase the range and diversity of voices of lived experience of chronic pain to inform implementation of the Framework for Pain Management Service Delivery. SG were keen to gather feedback from seldom heard voices within the chronic pain community, i.e. individuals who have not been involved in previous research or advocacy work related to chronic pain.
- 1.13. TLB worked with an external recruitment agency, Taylor Mackenzie, to recruit members of the panel. Taylor Mackenzie promoted the opportunity to contacts within their research database, and took interested parties through an eligibility screener which was designed by TLB.
- 1.14. A sampling framework was designed to ensure diversity within the panel across participants' experiences, circumstances, and characteristics and to reflect the available evidence on the demographics of chronic pain in the UK. Based on this, a panel of 16 individuals from across Scotland with lived experience of chronic pain was assembled. The size of the panel, while limited, was deemed to be reasonable given the depth of work required, iterative nature of the anticipated engagement with panel members, and the resource parameters of the research.

The demographics of the panel are shown in Figure 1.

Figure 1: Panel demographics

Demographic	Breakdown
Gender	44% male (7) 56% female (9)
Age	19% aged 18-30 (3) 31% aged 31-54 (5) 50% aged 55+ (8)
Ethnicity	81% White British (13) 13% mixed/multiple ethnic groups (2) 6% Asian – Pakistani (1)
Location	25% Central Scotland (4) 44% Urban/City (7) 19% Rural (3) 13% Remote rural (2)
Socio-economic status	50% B-C1 socio-economic group (8) 50% C2-E socio-economic group (8)
Impact of pain	19% No impact (3) 44% Little/low impact (7) 38% High impact (6)

Timescales

- 1.15. Effective project management and work planning are critical to ensuring smooth delivery and achievement of milestones. We have checked the capacity for our team members and can confirm we can complete the work in the timescale available. The project timeline is set out below:

What	When
SG to share draft proposal with SLWG A membership for input	w/c 31 st October
TLB, SG and SLWG A to discuss and finalise proposal	SLWG Meeting 7 th November
TLB to develop and finalise research tools	By 10th November
TLB to engage with the panel across in the week beginning 14th November, followed by analysis and reporting	w/c 14 November
TLB share draft findings with SG	30 November
TLB discuss findings with SG	1st December
TLB present to SLWGA	5th December

Suggested questions

- 1.16. See Appendix 2 for the user research draft discussion guide.

Analysis and reporting

- 1.17. Our team have a robust process of qualitative analyses. All discussions in user research sessions are transcribed. This ensures that we fully capture data from participants and allows us to take a team approach to data analyses. We read this content and, through discussion of the transcriptions, the team identify important themes, evidence and examples in relation to project outcomes and evaluation aims. The key research objectives, learning and outcomes are used to create a codification framework to support thematic analysis.
- 1.18. Working as a team at this key stage creates a robust environment for data analysis where our researchers' views are presented, challenged and discussed before we reach a collective conclusion for presentation to the client. If we can, we will involve lived experience stakeholders in this process to ensure validity.
- 1.19. The Lines Between are experienced at writing timely, useful reports and are expert in clear and effective communication. We will write the final report in such a way that these can easily be interpreted to inform change.

Quality assurance

- 1.20. TLB has fully defined and robust quality assurance provisions which includes all key activities, checks and senior staff sign-off points. This means that we follow a 'right first time' strategy. Steps in the process include:
- Providing and monitoring against a detailed timetable, showing responsibilities and key milestones.
 - Quality checking at all stages in line with, and often exceeding, those demanded by the quality standards.
 - Procedures governing approval and sign-off at all stages, with all research materials reviewed and signed off at least at Manager or Director level prior to being sent to the client.
 - Sign-off from clients at each decision-making stage to indicate approval.
 - Regular cycles of internal audits are embedded in our core processes feeding into ongoing process, capacity and capability improvement across the organisation.
 - Monthly staff supervision meetings and a team-based approach promoting peer review and learning.
- 1.21. As project manager, Lorraine will provide regular progress updates by email followed by a brief update meeting by video conference. We suggest that these take place on a weekly basis.

FOI - 202300342230 – document 36

From: REDACTED @gov.scot>
Sent: Thursday, 03 November 2022 14:26
To: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>
Cc: REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>
Subject: RE: Chronic Pain Panel - weekly progress update

Hi Lorraine

First of all, huge thanks to you and **REDACTED** (and the team) for all the work on the report. We are content with the changes proposed and have made some very minor changes which don't need further input/ action from TLB.

For your records, we intend to publish the attached version (without the tracked changes, and noting some design features may change depending on feedback from SG web publishing team e.g. accessibility etc.)

Agree we don't need the meeting this evening and great to hear the Panel are ready to go!

[OUT OF SCOPE].

REDACTED – we look forward to you joining us on Monday.

Best wishes
REDACTED

REDACTED
Senior Policy Manager – Chronic Pain
Clinical Priorities
Planning and Quality Division

From: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Sent: 03 November 2022 11:02
To: **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Subject: Re: Chronic Pain Panel - weekly progress update

Hi **REDACTED**

Thanks to a sterling effort by **REDACTED**, we have completed the revisions to the draft report and attach a final version, with an exec summary, for you to review. See attached. We have used tracked changes to show the edits, so you can review the alternations, and posed one question for you in comments (re: source of hyperbaric oxygen treatment).

The draft question schedule for the user research will follow later today.

I will be out of office next week so if you have any questions, please liaise with **REDACTED** and I can pick up anything urgent on my return.

Pleased to confirm that arrangements are in place with the Pain Panel members for the user research in the week beginning 14th November.

Not sure we need the scheduled catch-up today? I'll assume not - but won't book anything else at that time so if you do want to meet, let me know.

Best wishes

Lorraine

On Wed, Nov 2, 2022 at 11:55 AM <REDACTED@gov.scot> wrote:

Hi Lorraine

That's great to hear, thanks. If we could get the report as soon as possible that would be great – appreciate this might slightly impact the discussion guide.

Thanks again for your flexibility.

Best wishes

REDACTED

REDACTED

Senior Policy Manager – Chronic Pain

Clinical Priorities

Planning and Quality Division

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>

Sent: 02 November 2022 11:52

To: REDACTED@gov.scot>

Cc: REDACTED@thelinesbetween.co.uk; REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>

Subject: Re: Chronic Pain Panel - weekly progress update

Hi REDACTED, we can have the report to you by Friday lunchtime - would that work for you?

If you need it sooner, we could pause work on developing the discussion guide and prioritise the report to get that to you a little earlier, by first thing Friday morning?

Best wishes

Lorraine

On Wed, Nov 2, 2022 at 11:27 AM <REDACTED@gov.scot> wrote:

Hi Lorraine

Thanks for this, we'll review and get back to you if any questions on the proposal. On the report, we've now had confirmation of the debate date and internal deadlines, and **have been asked to provide a copy of the report to Ministers by the end of this week**. Do you think that's at all possible?

For Monday, I think it would be helpful if REDACTED can talk through it to ensure clarity for everyone.

Thanks

REDACTED

REDACTED

Senior Policy Manager – Chronic Pain

Clinical Priorities

Planning and Quality Division

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>

Sent: 02 November 2022 10:01

To: REDACTED@gov.scot>

Cc: REDACTED@thelinesbetween.co.uk; REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>

Subject: Re: Chronic Pain Panel - weekly progress update

Dear REDACTED

As promised, please find a summary proposal attached which sets out the key features of the user research activity. We are working on Appendix 2 - the draft question schedule and will send that on today or tomorrow.

Re: timetable for the revised report, will have that to you on Monday

Don't hesitate to let me know if you require any changes or clarifications before you share it with the SLWG.

Do you need **REDACTED** to talk through the paper at the meeting on Monday, or will your team be leading on any discussion?

**FOI - 202300342230 document 36a – – exemption - Section 27: (1)
Information intended for future publication**

FOI - 202300342230 – document 37

From: **REDACTED** @gov.scot>

Sent: Thursday, 03 November 2022 14:51

To: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>; **REDACTED** @gov.scot>

cc: **REDACTED** @thelinesbetween.co.uk; **REDACTED** @gov.scot>; **REDACTED**

@gov.scot>

Subject: RE: Chronic Pain Panel - weekly progress update

Hello Lorraine,

Replying for SG Policy

Thank you very much indeed for this proposal – think exactly what needed and will be of real help to SLWG in understanding the work ahead.

Couple of points of clarification for me, however these might be covered in DG:

- references to relevant 'authority' is useful, thank you. Keen that we include peers here, perhaps in probes
- albeit this is a panel exercise, is there provision for Ps to do task/s alone at some point, to reflect usual search behaviours? E.g. might they be given a scenario to explore on NHS Inform and think aloud or report back to group on the usefulness (or otherwise) of what they find?

Thank you for offer that **REDACTED** could talk through paper on Monday, I think that would be very helpful, just to do a brief summary and invite/answer questions. We have yet to confirm who in Policy team will attend and will let you know nearer the time. One key thing would want to emphasise is that if anyone asks for an area to be added to e.g. DG, we need to be clear that if something is added, something else needs to be removed (re: time constraints). Whilst we understand this, members of SLWG might not be in the business of commissioning user research, so just good to bear in mind.

To check – when would Appendix 2 be ready? Then we can work out whether to send to SLWG with/without that so they have papers in advance of meeting

Best,

REDACTED

FOI - 202300342230 – document 38

From: REDACTED @thelinesbetween.co.uk>
Sent: Friday, 04 November 2022 09:57
To: REDACTED @gov.scot>
Cc: REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk>
Subject: Re: Chronic Pain Panel - weekly progress update

Hi REDACTED,

Glad you are pleased with the discussion guide. I've made the edits and attached one version with tracked changes and another clean version that can be sent to the SLWG.

Have a lovely weekend and look forward to seeing you all on Monday.

REDACTED

On Thu, Nov 3, 2022 at 5:50 PM <REDACTED @gov.scot> wrote:

Thank you very much, Lorraine.

Think this will elicit some very useful responses

Have marked up a few comments – grateful if you or REDACTED can review and return to us. We will then get out to the SLWG

Best,

REDACTED

From: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>
Sent: 03 November 2022 16:30
To: REDACTED @gov.scot>
Cc: REDACTED @gov.scot>; REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>; REDACTED @gov.scot>
Subject: Re: Chronic Pain Panel - weekly progress update

HI REDACTED

No problem - please find the draft discussion guide attached, which addresses the points raised by your policy colleagues.

It's called Appendix 1. (Why I referred to it as Appendix 2 is a mystery not even known to me!)

Best wishes

Lorraine

FOI - 202300342230 document 36a and B – exemption - Section 27: (1) Information intended for future publication

FOI - 202300342230 – document 39

From: REDACTED @thelinesbetween.co.uk>
Sent: Monday, 14 November 2022 13:10
To: REDACTED gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>
Cc: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>
Subject: Chronic pain panel timescales

Hello everyone,

This morning I was debriefing Lorraine on the last SLWG meeting and I just wanted to double-check the timescales for Phase 2 of the project, as what was agreed at the meeting is slightly different from what is set out in our proposal.

At the SLWG meeting, we agreed that on 5th Dec, TLB would present interim findings to the SLWG about our engagement with the panel about NHS Inform's chronic pain webpage. Then, we would submit a fuller report in January.

However, our proposal states that the draft report will be submitted to SG on 30 Nov, then presented to the SLWG on 5th Dec, and there is no mention of the Jan deadline.

We think it is best to proceed with the first option as agreed at the SLWG. We now have some fieldwork planned for 28th Nov (this was to allow the panel sufficient time to complete the follow-up exercise about the self help guide) which would mean a very quick turnaround to get a full report ready in advance of the SLWG meeting.

I have summarised changes in the tables below:

OLD TIMESCALES		PROPOSED NEW TIMESCALES	
Fieldwork with panel	14 – 21 Nov	Fieldwork with panel	14 – 28 Nov
Draft report submitted to SG	30 Nov	Draft interim findings to SG	30 Nov
Findings presented to SLWG	5 Dec	Interim findings presented to SLWG	5 Dec
Contract end	Dec 22	Draft report submitted to SG	Jan 23
		Draft report presented to SLWG	Jan 23
		Contract end	Jan 23

Hope this all looks ok to you, just let me know if there's anything you'd like to discuss.

I also wanted to let you know that we had our first Phase 2 engagement with a panel member this morning. The discussion guide worked really well, and there is already some really interesting (and highly positive!) feedback coming out about the site.

Best wishes,

REDACTED

REDACTED | Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: **REDACTED**
www.thelinesbetween.co.uk | @thelinesbetweet

FOI - 202300342230 – document 40

From: **REDACTED**@gov.scot>
Sent: Wednesday, 16 November 2022 11:25
To: **REDACTED** @thelinesbetween.co.uk>; **REDACTED** @gov.scot>;
REDACTED.scot>
Cc: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Subject: RE: Chronic pain panel timescales

Thank for this. Yes timescales are ok

Kindest regards,

REDACTED
Policy Manager – Chronic Pain and Endometriosis
Clinical Priorities
Planning and Quality Division

FOI - 202300342230 – document 41

From: **REDACTED**@thelinesbetween.co.uk>
Sent: Thursday, 17 November 2022 11:18
To: **REDACTED**@gov.scot> @gov.scot>; **REDACTED**@gov.scot> @gov.scot>;
REDACTED@gov.scot>>
Cc: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Subject: Chronic pain lived experience panel weekly update

Hi **REDACTED**, **REDACTED** and **REDACTED**

Hope you've all had a great week so far. I caught a bit of the debate yesterday and it was really interesting; I found Christine Grahame's speech about her own experiences of living

with chronic back pain particularly impactful. And it was really interesting to hear a lot of the issues that have been raised by the panel discussed in parliament too.

I'm getting in touch with another update: **The project is ON SCHEDULE**

Since our last update, we have:

- Submitted an amended timetable (thanks for confirmation that we can go ahead with this)
- Commenced fieldwork on Project 2
 - So far, we've had 2 focus groups and 3 telephone interviews. There is one more focus group to be held this afternoon
- Started setting up the next wave of fieldwork with the panel

Next week we will:

- Begin analysis of transcripts of this week's focus groups and interviews

Notes for SG

The panel are engaging really well and sharing a lot of insight. However there has been one small issue; one member of the panel did not feel comfortable taking part in the NHS Inform feedback task, or the follow-up self-help guide task. She is an older lady and a self-confessed technophobe, and she said she would feel really out of her depth accessing the website, even with my support.

Hope that's a helpful update, let me know if I can provide any more info.

Best wishes,

REDACTED

REDACTED The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: **REDACTED**
www.thelinesbetween.co.uk | @thelinesbetweeet

FOI - 202300342230 – document 42

From: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>
Sent: Wednesday, 23 November 2022 11:43
To: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>
Cc: **REDACTED** @thelinesbetween.co.uk>
Subject: Early weekly progress update

Dear **REDACTED**, **REDACTED** and **REDACTED**

I am sending an early progress update [**OUT OF SCOPE**]

Pleased to report that everything is on track - groups and interviews went well last week and are being transcribed, and we're on schedule to share the draft interim findings report with you next week.

[OUT OF SCOPE]

Many apologies, but I need to ask that we skip tomorrow's catch-up due to the strike. Don't hesitate to let me know if you have any questions or want to rearrange it to a time early next week instead. If not, I will look forward to catching up next week.

Best wishes

Lorraine

--

Lorraine Simpson | Managing Director | The Lines Between Ltd. | Accessible Social Research
|

REDACTED | www.thelinesbetween.co.uk | @thelinesbetweet

FOI - 202300342230 – document 43

From: **REDACTED** @thelinesbetween.co.uk<

Sent: Wednesday, 30 November 2022 17:05

To: **REDACTED** @gov.scot>; **REDACTED** @gov.scot>; **REDACTED** @gov.scot>

Cc: Lorraine Simpson <**REDACTED** @thelinesbetween.co.uk>

Subject: Presentation of emerging findings for SLWG

Hi **REDACTED**, **REDACTED** and **REDACTED**,

Hope you're all doing well. As agreed, I've attached the emerging findings from Wave 2 of our consultation with the panel which I will be presenting to the SLWG on Monday 5th Dec.

Please review and let us know if you have any feedback or suggestions and we'll incorporate these before Monday's meeting.

Look forward to seeing you on tomorrow's catch up call.

Best wishes,

REDACTED

--

REDACTED | Senior Researcher
The Lines Between Ltd. | Accessible Social Research
3 Piershill Place, Edinburgh, EH8 7EH
t: 0131 235 2012 | m: **REDACTED**
www.thelinesbetween.co.uk | @thelinesbetweet

**FOI - 202300342230 – document 43a – exemption - Section 27: (1)
Information intended for future publication**

FOI - 202300342230 – document 44

From: REDACTED @thelinesbetween.co.uk>
Sent: Thursday, 01 December 2022 12:37
To: REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>
Cc: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>
Subject: Chronic pain lived experience panel weekly update

Hi REDACTED, REDACTED and REDACTED,

I'm getting in touch with another update: **The project is ON SCHEDULE**

Since our last update, we:

- Consulted with the panel again about the NHS Inform chronic pain self help guide
 - 14 out of 16 panel members took part in this exercise - 1 withdrew as she was uncomfortable using the internet and another had a last minute medical appointment
- Shared with you a draft of the interim findings from Project 2

Next week we will:

- Present interim findings from Project 2 to the SLWG on Mon 5th Dec
- Begin working on the full Project 2 report

Notes for SG

Yesterday, Lorraine received a call from REDACTED who is a member of a Cross Party Steering Group about chronic pain. She'd read the Project 1 report and had some questions for us about our work with the panel, including how they were recruited. We said we'd need to consult with you before sharing any further information, so hopefully we can discuss this later on today. We'd also like to discuss sending a copy of the report to the members of the panel - some were keen to see the outputs of their involvement.

Hope that's a helpful update, look forward to catching up this afternoon.

Best wishes,

REDACTED

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From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Wednesday, 07 December 2022 16:45
To: REDACTED@thelinesbetween.co.uk>
Cc: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>
Subject: Re: Chronic pain lived experience panel weekly update

Hi REDACTED, REDACTED and REDACTED

An early update [OUT OF SCOPE] Pleased to report the **project is ON SCHEDULE**

Since our last update, we have:

- Presented the interim findings from Project 2 to the SLWG - I hope Sharon will agree that the presentation was well received! Encouraging to hear how useful group members found the emerging findings - I think the lived experience perspective was highly valued. In some cases, the findings validated issues that the group has identified through their own scoping activity; I think it also drew their attention to some conflicting interpretations of guidance and tone among panel members; and other issues that had not occurred to them.
- REDACTED also shared the published report with the panel members. We had lovely feedback from one participant, who said:

"Thanks for sending this out...it was quite emotional seeing this collated together and also seeing the quotes that I knew I had said! But at the same time, I think this is crucial in trying to understand chronic pain further and hopefully there will be more time and money invested in further research in order to be able to offer services and a wider variety of treatments that benefit people living with chronic pain. Thanks again."

Next week we will:

- Continue working on the full Project 2 report.

From our perspective, there's no need for a meeting tomorrow (and I will be on leave) but if there's anything urgent REDACTED is available to speak tomorrow and I can pick up emails on Friday.

Hope this update is helpful.

Lorraine

FOI - 202300342230 – document 46

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>
Sent: Thursday, 15 December 2022 10:52
To: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>
Cc: REDACTED@thelinesbetween.co.uk>
Subject: Re: Chronic pain lived experience panel weekly update

Hi REDACTED, REDACTED and REDACTED

Pleased to report the **project is ON SCHEDULE**

Since our last update, we have:

- Received completed transcripts from the most recent group discussions and started the full analysis process.

Next week we will:

- Continue the analysis.
- Respond to the question re: the Project 1 report from a CPG member - will have that to you and REDACTED by Tuesday.

From our perspective, there's no need for a meeting today (but we can have it if there is anything specific you wish to talk through - just let me know in that case). **OUT OF SCOPE**

Hope this update is helpful.

Lorraine

FOI - 202300342230 – document 47

From: Lorraine Simpson <REDACTED@thelinesbetween.co.uk>

Sent: Thursday, 12 January 2023 14:01

To: REDACTED@gov.scot>; REDACTED@gov.scot>; REDACTED@gov.scot>

Cc: REDACTED@thelinesbetween.co.uk>

Subject: Re: Chronic pain lived experience panel weekly update

Hi all

Hello in 2023! Pleased to report the **project is ON SCHEDULE**

Since our last update, we have:

- Continued the full analysis and reporting process; we are on track to have the report to you by the end of January (currently planning to submit the report in the week beginning 23rd Jan).

Next week we will:

- Continue the analysis and reporting.
- Attend the SLWG on Monday

Looking forward to the catch-up later, from our perspective

- It would be good to know more about what the SLWG will cover on Monday and receive the details for the MS Teams event

- Wanted to let you know we had another email from the person who asked the question about the Phase 1 report before Christmas. It seems they found the question response helpful. They got in touch to ask if the report could be revised to include the additional information. I directed them to you and have not heard anything since.

Hope this update is helpful.

Lorraine

FOI - 202300342230 – document 48

From: REDACTED @thelinesbetween.co.uk>

Sent: Thursday, 19 January 2023 12:47

To: REDACTED @gov.scot>; REDACTED @gov.scot>; REDACTED @gov.scot>

Cc: REDACTED @thelinesbetween.co.uk>

Subject: Re: Chronic pain lived experience panel weekly update

Hi all

Pleased to report the **project is ON SCHEDULE**

Since our last update, we have:

- Continued the full analysis and reporting process; we are on track to have the report to you by the end of January (currently planning to submit the report in the week beginning 23rd Jan).
- Attended the SLWG on Monday; they seemed pleased with the progress update on the report that REDACTED provided.

Next week we will:

- Finalise the report; we anticipate sending it to you next Wednesday.

From our perspective, there's no need for this afternoon's catch-up, so I will cancel the meeting - but if you do want to discuss anything let me know and I can reinstate the meeting and hop on the call at 4.30

Hope this update is helpful.

Lorraine

FOI - 202300342230 – document 49

From: Lorraine Simpson <REDACTED @thelinesbetween.co.uk>

Sent: Wednesday, 25 January 2023 10:29

To: REDACTED @gov.scot>

Cc: REDACTED @thelinesbetween.co.uk; REDACTED @gov.scot>;

REDACTED@gov.scot>

Subject: Re: Chronic pain lived experience panel weekly update

Dear REDACTED, REDACTED and REDACTED

As promised, please find our draft report attached. I hope you find this useful and informative; I think the information will be of value to the SLWG.

The final draft will reflect any feedback from you and include an exec summary - there might also be value in including a description of next steps from the SG in the conclusions; if you would like us to incorporate those, please send a summary.

We look forward to receiving your feedback.

Best wishes

Lorraine

**FOI - 202300342230 – document 49a – exemption - Section 27: (1)
Information intended for future publication**