European Reference Network | ERN eUROGEN
Rare Uro-Recto-Genital Diseases & Complex Conditions

Rare PREPARE: A Multi-Stakeholder Workshop to Co-Design a Rare Diseases and Complex Conditions Pre-Consultation Tool to Enhance Patient Readiness and Experience

Consensus Building Workshop on a Question Prompt List (QPL) – Results and Discussions

v. 2026-11-11

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1. MEETING DETAILS

Meeting	Rare PREPARE Consensus Building Workshop (2-half-day meeting)
Date – Day 1	30 September 2026
Date – Day 2	1 October 2026
Times	Day 1: arrival/lunch from 13:00, programme 14:00–17:30, followed by networking dinner (as per agenda) Day 2: 08:30–13:00, followed by closing lunch (as per agenda)
Venue	Radboudumc Experience Center, Nijmegen, The Netherlands
Meeting lead	John Osborne – ERN eUROGEN ePAG Chair
Facilitators	Nora Lázaro and Inés Hernando – EURORDIS; Jen Tidman and Parmida Anvary – ERN eUROGEN Coordination Team
Funding	This project has received funding from the European Union's Horizon Europe research and innovation programme under ERDERA programme GA N° 101156595. The views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union, who cannot be held responsible for them.

2. PARTICIPANTS

2.1. Panel

No.	Name	ERN/Organisation	Role	Country
1	Anna Radová	ERN EYE	Patient	Czechia
2	Arie Parnham	ERN eUROGEN	Clinician	United Kingdom
3	Caroline Love	ERNICA / ERN LUNG	Patient	United Kingdom
4	Chrysanthi Skalioti	ERKNet	Clinician	Greece
5	Delian Hofman	ERN LUNG	Clinician	The Netherlands
6	Ester Costafreda	ERN GuardHeart	Patient	Spain
7	Eszter Szabo	ERN ITHACA	Patient	Hungary
8	Ieva Bāgante	ERN CRANIO	Clinician	Latvia
9	Ilze Akota	ERN CRANIO	Clinician	Latvia
10	Iris Pelsma	Endo ERN	Clinician	The Netherlands
11	John Osborne	ERN eUROGEN	Patient	United Kingdom
12	Kate Tyler	ERN eUROGEN	Patient	United Kingdom
13	Katerina Papadopoulou	ERN CRANIO	Clinician	Republic of Ireland
14	Marizela Kljajić	ERN CRANIO	Clinician	Sweden
15	Olga Kudamanova	ERN CRANIO	Patient	France
16	Pınar Ergenekon	ERN LUNG	Clinician	Turkey

2.2. Other attendees

No.	Name	ERN/Organisation	Role	Country
1	Peter Mulders	ERN eUROGEN	Principal Applicant / Host	The Netherlands
2	Jen Tidman	ERN eUROGEN	Facilitator	The Netherlands
3	Parmida Anvary	ERN eUROGEN	Facilitator	The Netherlands
4	Inés Hernando	EURORDIS	Facilitator	Spain
5	Nora Lázaro	EURORDIS	Facilitator	Spain

2.3. Apologies

No.	Name	ERN/Organisation	Stakeholder group	Country
1	Coralie Peter Bouillot	ERN ReCONNET	Patient	France
2	Elena Arbelo	ERN GuardHeart	Clinician	Spain
3	Friedemann Paul	ERN EYE	Clinician	Germany
4	Gareth Davies	ERN CRANIO	Patient (Co-Applicant)	The Netherlands
5	Giulia Stella	ERN LUNG	Clinician	Italy
6	Marie Christine Ouillade	ERN NMD	Patient	France
7	Rachel Giles	ERKNet	Patient	The Netherlands
8	Rob Cornes	ERN eUROGEN	Patient (Co-Applicant)	United Kingdom
9	Silvia Aguilera	ERN ReCONNET	Patient (Co-Applicant)	Spain
10	Susana Carvajal	ERKNet	Patient	Spain
11	Tomas Buchler	ERN eUROGEN	Clinician (Co-Applicant)	Czechia
12	Yuliya Matyushenko	ERN NMD	Patient	France

2.4. Attendance summary

	Day 1	Day 2
Total participants (voters)	16	16
Patient representatives	7	7
Clinicians	9	9

3. BACKGROUND, OBJECTIVES AND OUTCOMES AT A GLANCE

3.1. Background and objectives

The workshop brought together the Rare PREPARE core working group, panel members, patient representatives and clinicians to review, refine and agree on a list of 10 prompts for the Rare PREPARE Question Prompt List (QPL). It built on the rating and ranking carried out by the core working group and the panel throughout 2026. The meeting also explored future opportunities for collaboration on patient experience.

The starting point was a set of 71 categories related to patient experience, organised into 11 domains. Through team rating, the core working group shortlisted 31 categories and 5 domains, then narrowed them to 10 categories across 5 domains through forced ranking and consensus. For these 10 categories, the core working group drafted 91 prompts; after duplicates were removed and the list was reviewed, 85 prompts remained.

In April 2026, panel members rated the 85 prompts against two criteria: (i) how likely the topic is to be missed if not explicitly prompted, and (ii) how significant the potential impact on the patient's care or outcomes is if the topic is raised during a consultation. In a second step, the panel ranked the 30 shortlisted prompts using the same two criteria, producing a Top 20 and a bench of 10 prompts (ranks 21–30). After reviewing these results, the core working group agreed to rescue 2 prompts for the bench list.

The consensus workshop aimed to discuss the Top 20 prompts and, using consensus techniques, agree on a list of 10 to display prominently in the QPL.

3.2. Outcomes of consensus at a glance

Outcome	Number	Prompt numbers
Prompts rescued from the bench (wildcard, Day 1)	1	8. “I need to understand the costs related to my treatment I will have to cover” – reworded as “I need to understand what are the direct and indirect costs linked to my condition”
Prompts agreed by full consensus (all at 3 or higher)	10	4, 6, 8, 9 (combined with 14), 10, 26 (combined with 83), 29, 31, 39, 43 New wording: 6, 8, 9, 10, 26, 29, 43
Prompts with referred to core group for rewording	2	Prompt 4 refine wording. Full list – review the formulation of prompts to ensure consistency, review the language to make all of them accessible and discuss whether examples might be required for some prompts.
Prompts discarded (including 2 merged into other prompts)	11	19, 22, 33, 34, 35, 38, 56, 62, 72, 14 (merged into 9), 83 (merged into 26)
New prompts proposed for core group review	0	

3.3. Key messages from “Let Ideas Flow Session”

- Three champions each turned a priority theme from the introductions into a goal for the next 1-2 years. Anna Radová proposed basic information on Usher syndrome after diagnosis in all EU/EEA languages. Kate Tyler proposed better outreach to adults with VACTERL. Katerina Papadopoulou proposed communication training for rare disease care teams, along with simple prompts that help patients bring one personal question to their consultation.
- For Usher syndrome, the group suggested adapting existing content rather than starting from scratch. A Swedish rare disease website (Socialstyrelsen) could be reviewed by expert clinicians and patient representatives, subject to copyright, so that ERN EYE can produce and translate a leaflet. Whoever delivers the diagnosis would then hand it over or share a link. Anna can seek support from ERN EYE and Retina International.
- For VACTERL, participants noted that no cross-ERN group currently covers the condition. They proposed setting one up across ERN LUNG, ERNICA and ERN eUROGEN, possibly starting with a joint webinar. Clinicians would be asked to point

patients to Kate's patient organisation, using the patient journey developed by the ERN eUROGEN ePAG. A mentorship programme should include a psychologist to help mentors and mentees set and maintain boundaries.

- For people-centred care, the group agreed that training should be short, practical and easy to fit into clinical work, and should be developed by clinicians with rare disease experience. Letters, posters or an app should first be tested with small groups of patient representatives before a hospital trial. Discussion also noted that some patients prefer a purely medical consultation and may find personal questions intrusive.
- The same obstacles came up for every theme: securing funding, getting the relevant ERNs on board, and getting clinicians to take part at clinic level, whether by sharing leaflets, referring patients or making time for training.

4. CONSENSUS METHODS AND DECISION RULES

Stage	Method	Decision rule
Day 1 – Wildcard (bench: ranked 21–32)	Slido vote: Is any item in the 21-32 range essential to discuss today?	Up to 3 items are rescued if each receives at least 9 votes; rescued items join the 20, the others stay on the bench
Day 1 – Session 1 (patient representatives and clinicians in separate groups)	Individual silent reading and reflection; Slido vote to discard prompts; group discussion; five-finger voting on the Top 10	Group agrees on a list acceptable to everyone; concerns and disagreements are noted. Consensus on the list of Top 10 if 3 fingers or higher.
Day 2 – Session 2 (mixed groups)	Two rounds of silent individual Slido voting, group discussion and five-finger voting	Consensus on the list of Top 10 if 3 fingers or higher; if no consensus after 2 rounds, this is noted
Day 2 – Session 3 (plenary)	Structured consensus discussion; individual voting to complete the list; final five-finger vote on the 10 prompts	Everyone at 3 or higher: accepted by consensus. At least two thirds at 3 or higher but some at 1 or 2: accepted by qualified approval; concerns recorded. Fewer than two-thirds at 3 or higher: no agreement; referred to the core group and noted as not agreed.

Criteria used when selecting prompts to discard:

- A balanced list for surgical and non-surgical conditions.
- Items relevant for both adult-onset and childhood-onset conditions.

Five-finger scale as used in the meeting:

Fingers	Meaning
1	Strongly support
2	Support
3	Can support, although I have reservations
4	Cannot support without changes
5	Strong objection or serious concern

5. DAY 1 – 30 SEPTEMBER 2026

5.1. Welcome and introductions

Prof. Peter Mulders, ERN eUROGEN Coordinator, opened the meeting by welcoming everyone to Radboudumc in Nijmegen. He stressed that Rare PREPARE is a collective effort, built by patient representatives and clinicians from different ERNs working side by side, and thanked the ERN eUROGEN Coordination Team and EURORDIS for their support so far. Participants then introduced themselves, sharing their name, country, condition or area of experience, their top three priorities for improving quality of life or patient experience, and one fun fact about themselves. John Osborne, ERN eUROGEN ePAG Chair, who initiated the project, closed the opening session by presenting the workshop goals and agenda and setting out a few ground rules for the two days.

5.1.1 Priorities and themes emerging from the introductions

No.	Theme / priority	Raised by (number)	Description of theme
1	People-centred care	17	Continuity & coordination of care across the whole life course, and also psychologically informed healthcare across the MDT
2	The Right to Know	11	Information, transparency & disclosure as preconditions for shared decision-making
3	Evidence based healthcare	11	Making better use of evidence to inform healthcare practice
4	Community, Visibility & Collective Voice	10	Connecting people through peer support, patient groups and lived experience, raising awareness of rare conditions across society and among professionals, and strengthening the voice of people with rare conditions in research, policy and public life.
5	Mental well-being and psychological support	9	Integrated mental well-being and psychological support in the care provided
6	Timely access to specialised care & diagnosis	7	Reducing diagnostic delay through early and accurate diagnosis and timely referral to expert care, including fair access to specialist testing and screening.
7	Equity	3	Integrating the equity dimension in healthcare and other aspects of daily life

5.2. Question Prompt List foundation

5.2.1 Presentations and Q&A

Presentation	Key points
Background: methodology and previous work of the core working group, rating and ranking methodology	• **Reminder of the scope of the QPL**: a tool to prepare consultations with specialists for rare and complex conditions. Developed for adults in their first year of diagnosis, and caregivers of people who are in their first year of diagnosis. • **Brief explanation of the methodology**: informed by findings from an existing scoping review, which identified 71 categories organised across 11 domains. The core working group then prioritised these categories, selecting 10 categories across 5 key domains. Based on these prioritised categories, the group drafted an initial set of 91 prompts. After review and refinement, the list was reduced to 85 prompts, which were then evaluated using a modified Delphi approach. The process comprised three rounds: (1) a rating exercise conducted by an expert panel that reduced the list from 85 to 30 prompts; (2) a ranking exercise that further narrowed the list from 30 to 20 prompts; and (3) this face-to-face consensus meeting, during which participants will discuss and agree on the final Top 10 prompts.
Design: length, format and delivery method alternatives	• **Delivery methods envisaged**: - **Clinicians** may send it to patients or caregivers either: before the consultation, asking them to complete and return it so they both know in advance what topics the patient or caregiver would like to address, OR; when they arrive at the clinic to complete before the consultation begins, in the waiting room. Then both can review it together during the appointment - **Patients and caregivers** may use it independently as a memory prompt to prepare for their appointments. • Description of components and format of the QPL, based on a literature review and feedback from experts (max. 4-page PDF, printable, English, plain language, accessible). • Visualisation of QPL (Mock-up): first impressions and immediate feedback (inclusion of date).
Panel rating and ranking results (Top 20 prompts as ranked by panel)	The ranked Top 20 and the full list of 32 prompts are tracked in Appendix A.

5.2.2 Wildcard exercise – bench items ranked 21–32 (Slido)

Rule: item is rescued if it receives at least 9 votes (maximum 3 items).

Panel Rank	Prompts "on the bench"	Slido votes (Total votes: 16)	Rescued Y/N	Comments
	Diagnosis and Treatment			
25	21. I find it difficult to tell if my symptoms are because of my condition or a side effect of my treatment	1	N	
21	25. I struggle to express myself during appointments. I find discussing my treatment intimidating and don't know how to express myself fully or properly	6	N	
30	32. I want support to adjust my treatment as my life circumstances may change	2	N	

Rescued by core team in June	8. I need to understand the costs related to my treatment I will have to cover	7	Y	Even if it did not reach the threshold of 9 votes, all participants agreed to reword it and rescue it: I need to understand what are the direct and indirect costs linked to my condition
	Comprehensiveness			
28	37. I find it difficult to look ahead. I need support to help me feel more confident about the future.	4	N	
	Self-management and support			
29	52. I need someone to explain my treatment to me in words I understand.	6	N	
27	53. I need to know what my treatment is supposed to do.	1	N	
26	58. I find it difficult to understand if my wellbeing needs are covered by my treatment plan	1	N	
	Continuity			
23	66. I need my GP to understand my condition	3	N	
Rescued by core team	64. I want to understand who is responsible for coordinating my care to ensure that all the doctors involved are kept up to date with my overall health needs	6	N	
	Trust			
22	82. I want to know if there are any patient versions of national medical guidelines for my condition	3	N	
24	85. My current treatment does not feel right for me. I need us to discuss other treatment options	5	N	

Items rescued and added to the list:

8. I need to understand what are the direct and indirect costs linked to my condition.

5.3. Session 1: review, refine and select 10 'must-haves' by stakeholder group

5.3.1 Breakout groups

	Group A – Patient representatives	Group B – Clinicians
Number of participants	7	9
Facilitator	IH	NL

5.3.2 Slido poll: prompts to discard

Individual voting after silent reading (3 min) and reflection (7 min). Record the number of participants who voted to discard each prompt, based on the two criteria (balance surgical/non-surgical; relevance to adult and childhood onset).

Prompt wording	Group A: discard votes	Group B: discard votes
4. I want to know what psychological or emotional support is available to me	0	5
6. I need help understanding how my diagnosis may affect my future and daily life	1	0
9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention	2	1
10. I want my personal goals or values considered when choosing treatment	4	2
14. I want to discuss whether my treatment benefits outweigh the side effects	4	8
19. I need to know what will happen if I miss part of my treatment	4	9
22. I need clear guidance on what to do if I feel unwell during or after treatment	5	8
26. I need to understand why changes are made to my treatment	5	6
29. I want help coordinating treatments across different teams	3	4
31. I find it difficult to stay motivated with long-term treatment	6	4
33. I find it difficult talking to those close to me	4	5
34. I need help to put feelings into words	5	8
35. I want to ask for help but not sure who or how	4	5
38. I find it difficult not to feel overwhelmed by my symptoms	6	9
39. I need to understand the impact on intimacy with those closest to me	4	5
43. I want to know how to access healthcare support	3	6
56. I need a simple calendar with dates and types of treatment	3	2
62. I want to discuss my hopes and what a realistic outcome from treatment could be	5	3
72. I find it difficult when different professionals give conflicting advice	4	2
83. I want to understand how decisions are made when evidence is limited	3	5
8. I need to understand what are the direct and indirect costs linked to my condition	0	1

5.3.3 Group discussion

Group A – Patient representatives

Discussion point	Summary of discussion	Outcome / action
Prompts requiring re-wording or better formulation	43. I want to know how to access healthcare support. I want to know how to access specialist care for my rare condition	Both prompts were re-drafted and added to the list for D2

Discussion point	Summary of discussion	Outcome / action
Prompts that would be better combined	Prompt 9 + Prompt 14 New wording combining benefits and side effects: 9. I need a clear explanation of the benefits and possible side effects of my treatment	Prompt 9 was reworded and added to the list for D2. Prompt 14 was removed from the list for D2 because duplicated
Critical gaps or concerns	None	
New prompts proposed	None	
Convergent views	Between 0-2 people voted to keep the following prompts (fully or mostly convergent) • 4. I want to know what psychological or emotional support is available to me (0) • 8. I need to understand what are the direct and indirect costs linked to my condition (0) • 6. I need help understanding how my diagnosis may affect my future and daily life (1) • 9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention (2) Between 5-7 people voted to discard the following prompts (fully or mostly convergent) • 31. I find it difficult to stay motivated with long-term treatment (6) • 38. I find it difficult not to feel overwhelmed by my symptoms (6) • 22. I need clear guidance on what to do if I feel unwell during or after treatment • 26. I need to understand why changes are made to my treatment (5) • 34. I need help to put feelings into words (5) • 62. I want to discuss my hopes and what a realistic outcome from treatment could be (5)	

Discussion point	Summary of discussion	Outcome / action
Divergent views	Disputed prompts (3-4 people voted to discard) were: • 29. I want help coordinating treatments across different teams (3) • 43. I want to know how to access healthcare support (3) • 56. I need a simple calendar with dates and types of treatment (3) • 83. I want to understand how decisions are made when evidence is limited (3) • 10. I want my personal goals or values considered when choosing treatment (4) • 14. I want to discuss whether my treatment benefits outweigh the side effects (4) • 19. I need to know what will happen if I miss part of my treatment (4) • 33. I find it difficult talking to those close to me (4) • 35. I want to ask for help but not sure who or how (4) • 39. I need to understand the impact on intimacy with those closest to me (4) • 72. I find it difficult when different professionals give conflicting advice (4)	**Prompt 43** was refined to clarify its sense and gain further support: "I want to know how to access specialist care for my rare condition" **Prompt 83** obtained further support from other group members during the discussion, when they realised that it was the only prompt covering the domain Trust. The group decided to combine p**rompts 14 + 9** and kept the new prompt in the Top 10 list. The group agreed to include **prompt 39** in the Top 10 list, given that people often have difficulties discussing intimacy in consultations.

Group B – Clinicians

Discussion point	Summary of discussion	Outcome / action
Prompts requiring re-wording or better formulation	**Prompt 9** - I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention For prompt 9, the group proposed replacing the word *treatment* with *options*.	**Prompt 9** - I need a clear explanation of the possible side effects of my *options*, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention

Discussion point	Summary of discussion	Outcome / action
Prompts that would be better combined	Several prompts related to emotional support received the same number of votes (5) • 4. I want to know what psychological or emotional support is available to me • 33. I find it difficult talking to those close to me • 35. I want to ask for help but not sure who or how • 39. I need to understand the impact on intimacy with those closest to me The Group discussed the possibility of merging these prompts, but did not have the time to propose a new wording. **Prompts 10 + 62** **Prompt 10**. I want my personal goals or values considered when choosing treatment **Prompt 62**. I want to discuss my hopes and what a realistic outcome from treatment could be The group discussed a possible overlap. They also raised the importance of taking into consideration the children's values/hopes too, not only those of carers (e.g. not having surgery during holidays)	Referred to core working group Prompt 10 was voted over Prompt 62
Critical gaps or concerns	**Prompt 9** - I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention The group noted the possibility of having side effects if there is no treatment, in order to understand the consequences and act on them. They noted that the prompt's current wording places responsibility on clinician. **Prompt 8**. I need to understand what are the direct and indirect costs linked to my condition The group remarked that it may depend on the specialty. **Prompt 56**. I need a simple calendar with dates and types of treatment The group considered this linked to the hospital's infrastructure and approach and saw a possible overlap with care coordination information.	
New prompts proposed	None	

Discussion point	Summary of discussion	Outcome / action
Convergent views	Between 0-2 people voted to keep the following prompts (fully or mostly convergent) • 6. I need help understanding how my diagnosis may affect my future and daily life, 0 • 9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention, 1 • 8. I need to understand what are the direct and indirect costs linked to my condition, 1 • 10. I want my personal goals or values considered when choosing treatment, 2 • 56. I need a simple calendar with dates and types of treatment, 2 • 72. I find it difficult when different professionals give conflicting advice, 2 Between 6-9 people voted to discard the following prompts (fully or mostly convergent): • 26. I need to understand why changes are made to my treatment, 6 • 43. I want to know how to access healthcare support, 6 • 14. I want to discuss whether my treatment benefits outweigh the side effects, 8 • 22. I need clear guidance on what to do if I feel unwell during or after treatment, 8 • 34. I need help to put feelings into words, 8 • 19. I need to know what will happen if I miss part of my treatment, 9 • 38. I find it difficult not to feel overwhelmed by my symptoms, 9	

Discussion point	Summary of discussion	Outcome / action
Divergent views	Disputed prompts (3-6 voted to discard) were: • 62. I want to discuss my hopes and what a realistic outcome from treatment could be, 3 • 29. I want help coordinating treatments across different teams, 4 • 31. I find it difficult to stay motivated with long-term treatment, 4 • 4. I want to know what psychological or emotional support is available to me, 5 • 33. I find it difficult talking to those close to me, 5 • 35. I want to ask for help but not sure who or how, 5 • 39. I need to understand the impact on intimacy with those closest to me, 5 • 83. I want to understand how decisions are made when evidence is limited, 5 • 26. I need to understand why changes are made to my treatment, 6 • 43. I want to know how to access healthcare support, 6	After the discussion, it was agreed that one prompt covering **Prompts 4, 33, 35 and 39** should be drafted, referring to psychological aspects. **Prompt 83** did not receive further support from other group members during the discussion, despite being the only prompt covering the domain Trust. The group agreed to leave it out.

5.3.4 Five-finger voting on the Top 10 list

Group A – Patient representatives: The group reached consensus on the list of Top 10 prompts with 5 persons expressing Strong Support (5) and 1 expressing Support (4).

Group B – Clinicians: The group reached consensus on the list of Top 10 prompts with 1 person expressing Strong Support (5); 4 expressing Support (4) and 4 expressing that can support with reservations (3). We did not have time to discuss those reservations.

5.3.5 Day 1 output: Top 10 lists compared

Patient representatives and clinicians agreed 6 of the 10 prompts in their Top 10 lists; 3 differed between the groups. Group A merged prompts 9 and 14 and reworded them, so they read slightly differently from the original prompts that were included in the clinician's Top 10 list.

Group A – Patient representatives	Group B – Clinicians	In both?
4. I want to know what psychological or emotional support is available to me	4. I want to know what psychological or emotional support is available to me	yes
6. I need help understanding how my diagnosis may affect my future and daily life	6. I need help understanding how my diagnosis may affect my future and daily life	yes
8. I need to understand what are the direct and indirect costs linked to my condition	8. I need to understand what are the direct and indirect costs linked to my condition	yes
9. I need a clear explanation of the benefits and possible side effects of my treatment *(combined with 14 and re-worded)*	9. I need a clear explanation of the possible side effects of my *options* including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention *(reworded)*	-

Group A – Patient representatives	Group B – Clinicians	In both?
10. I want my personal goals or values considered when choosing treatment	10. I want my personal goals or values considered when choosing treatment	yes
29. I want help coordinating treatments across different teams	29. I want help coordinating treatments across different teams	yes
39. I need to understand the impact on intimacy with those closest to me	31. I find it difficult to stay motivated with long-term treatment	no
56. I need a simple calendar with dates and types of treatment	56. I need a simple calendar with dates and types of treatment	yes
43. I want to know how to access specialist care for my rare condition (reworded)	62. I want to discuss my hopes and what a realistic outcome from treatment could be	no
83. I want to understand how decisions are made when evidence is limited	72. I find it difficult when different professionals give conflicting advice	no

5.3.6 Changes to the list of 20 prompts for Day 2

- **Prompt 8** was reworded and rescued: I need to understand what are the direct and indirect costs linked to my condition.
- **Prompt 9** was reworded: I need a clear explanation of the benefits and possible side effects of my treatment.
- **Prompt 14** was removed from the list, as it had been combined with prompt 9.
- **Prompt 43** was reworded: I want to know how to access specialist care for my condition.

6. DAY 2 – 1 OCTOBER 2026

6.1. Session 2: mixed groups agree on a Top 10

	Patient reps	Clinicians	Facilitator	Members
Mixed Group 1	4	4	IH	Arie Parnham, Delian Hofman, Ilze Akota, Katerina Papadopoulou John Osborne, Anna Radová, Caroline Love, Kate Tyler
Mixed Group 2	3	5	NL	Chrysanthi Skalioti, Ieva Bāgante, Iris Pelsma, Marizela Kljajić, Pınar Ergenekon Olga Kudamanova, Ester Costafreda, Eszter Szabo

6.1.1 Slido polls: individual voting to discard prompts

Prompt	G1 Round 1	G1 Round 2	G2 Round 1	G2 Round 2	Comment
4. I want to know what psychological or emotional support is available to me	0	0	0	0	
6. I need help understanding how my diagnosis may affect my future and daily life	1	0	0	0	Group 1 suggested a new wording. I need help understanding my diagnosis and how it may affect my future and daily life Group 2 discussed whether intimacy (prompt 39) could be considered as part of prompt 6
9. I need a clear explanation of the benefits and possible side effects of my treatment	0	0	0	0	
10. I want my personal goals or values considered when choosing treatment	3	2	1	1	Group 1 reworded the prompt slightly, replacing or with and: I want my personal goals and values considered when choosing treatment Group 2 saw overlap with prompt 62
19. I need to know what will happen if I miss part of my treatment	6	7	6	7	
22. I need clear guidance on what to do if I feel unwell during or after treatment	6	7	6	7	
26. I need to understand why changes are made to my treatment	3	0	7	8	Group 1 used for the second voting round a new wording: I need to understand how treatment decisions and changes are made when evidence is limited

Prompt	G1 Round 1	G1 Round 2	G2 Round 1	G2 Round 2	Comment
29. I want help coordinating treatments across different teams	2	0	3	3	Group 1 used in the second voting round a new wording. I want help coordinating treatments across different teams Group 2 agreed on rewording: prompt 9 - *I want help coordinating treatments and/or conflicting advice* (merged with prompt 72)
31. I find it difficult to stay motivated with long-term treatment	3	4	5	3	Group 2 agreed on the importance of this prompt as its linked to adherence to treatment, therefore included in TOP 10
33. I find it difficult talking to those close to me	5	7	6	8	
34. I need help to put feelings into words	5	0	8	8	
35. I want to ask for help but not sure who or how	4	6	6	8	
38. I find it difficult not to feel overwhelmed by my symptoms	5	6	8	7	
39. I need to understand the impact on intimacy with those closest to me	0	0	4	2	
43. I want to know how to access specialist care for my rare condition	4	3	1	1	
56. I need a simple calendar with dates and types of treatment	3	5	2	1	
62. I want to discuss my hopes and what a realistic outcome from treatment could be	2	4	5	5	Group 2 saw overlap with prompt 10
72. I find it difficult when different professionals give conflicting advice	3	5	3	3	Group 2 saw this prompt as part of Trust (in the specialist providing the advice/treatment). Decided to merge with prompt 29 and reword: *I want help coordinating treatments and/or conflicting advice*
83. I want to understand how decisions are made when evidence is limited	4	-	6	7	Group 1 combined this prompt with prompt 26 and removed it from the list for the second voting round, using the new wording: *I need to understand how treatment decisions and changes are made when evidence is limited*.
8. I need to understand what are the direct and indirect costs linked to my condition	1	0	1	1	

6.1.2 Group discussion

Discussion point	Mixed Group 1	Mixed Group 2
Reasons given for low-voted or discarded prompts		
Prompts quickly agreed as acceptable to everyone	The group converged on 8 prompts (0 to 2 votes on second voting) • 4. I want to know what psychological or emotional support is available to me • 6. I need help understanding how my diagnosis may affect my future and daily life • 9. I need a clear explanation of the benefits and possible side effects of my treatment • 29. I want help coordinating care across different teams • 39. I need to understand the impact on intimacy with those closest to me • 26. I need to understand how treatment decisions and changes are made when evidence is limited • 8. I need to understand what are the direct and indirect costs linked to my condition • 10. I want my personal goals and values considered when choosing treatment	The group converged on 8 prompts (0 to 2 votes on second voting) • 4. I want to know what psychological or emotional support is available to me , 0 • 6. I need help understanding how my diagnosis may affect my future and daily life , 0 • 9. I need a clear explanation of the benefits and possible side effects of my treatment , 0 • 10. I want my personal goals or values considered when choosing treatment , 1 • 43. I want to know how to access specialist care for my rare condition , 1 • 56. I need a simple calendar with dates and types of treatment , 1 • 8. I need to understand what are the direct and indirect costs linked to my condition, 1 • 39. I need to understand the impact on intimacy with those closest to me , 2
Application of the two criteria (surgical/non-surgical balance; adult/childhood onset)	Prompt 56. *I need a simple calendar with dates and types of treatment*. The group discussed the impact of discarding, as it was ranked as the number 1 prompt by the wider panel. This type of calendar might be more relevant for non-surgical conditions. Most participants believed that the calendar discussion could emerge in the discussion prompted by 29 - *I want help coordinating care across different teams.* They suggested adding examples to make this clearer in prompt 29: *I want help coordinating care across different teams. (e.g. a point of contact, a treatment plan, a simple calendar…etc.).* On the other hand, this could narrow the scope of this prompt if people read the list of examples as exhaustive. The group did not reach a final agreement, and the decision was referred to the core working group.	The group discussed at length merging **Prompts 72 and 29.** The group agreed to discard prompt 72 if combined it with prompt 29. They agreed on this working: *I want help coordinating treatments and/or conflicting advice* They combined these 2 prompts so that they could include **prompt 31** in the Top 10, about adherence to treatment: (*31. I find it difficult to stay motivated with long-term treatment)*

Discussion point	Mixed Group 1	Mixed Group 2
Points of disagreement/concerns	The group discussed at length the possibility of merging prompt 8 on costs with prompt 6, which refers to impact on future and daily life. They did not reach a final agreement and the decision was referred to the core working group. Finally, some participants raised concerns about the use of the QPL in certain countries where consultations are more clinician-led.	There were no major points of disagreement or concerns. The group ended the discussion before scheduled.

6.1.3 Final agreement – five-finger voting

Mixed Group 1: The group reached consensus on the list of Top 10 prompts through a five-finger voting process, with 6 persons expressing *Support* (4) and 1 expressing *Can support, although I have reservations* (3). The participant who voted 3 questioned whether the QPL would be used in the same way in healthcare settings where patients are less used to initiating questions or where decision-making is more clinician-led.

Mixed Group 2: The group reached consensus on the list of Top 10 prompts through a five-finger voting process, with 3 persons expressing Strong Support (5); and 5 persons expressing Support (4).

The Groups' Top 10 Prompts:

Mixed Group 1:

Top 10 Prompts
4. I want to know what psychological or emotional support is available to me
6. I need help understanding how my diagnosis may affect my future and daily life
9. I need a clear explanation of the benefits and possible side effects of my treatment
29. I want help coordinating care across different teams (new wording)
39. I need to understand the impact on intimacy with those closest to me
26. I need to understand how treatment decisions and changes are made when evidence is limited (new wording)
8. I need to understand what are the direct and indirect costs linked to my condition
10. I want my personal goals and values considered when choosing treatment (new wording)
43. I want to know how to access specialist care for my rare condition
31. I find it difficult to stay motivated with long-term treatment

Mixed Group 2:

Top 10 Prompts
4. I want to know what psychological or emotional support is available to me
6. I need help understanding how my diagnosis may affect my future and daily life
9. I need a clear explanation of the benefits and possible side effects of my treatment
10. I want my personal goals or values considered when choosing treatment
43. I want to know how to access specialist care for my rare condition
56. I need a simple calendar with dates and types of treatment
8. I need to understand what are the direct and indirect costs linked to my condition
39. I need to understand the impact on intimacy with those closest to me
29. I want help coordinating care and/or conflicting advice across different specialist (new wording)

31. I find it difficult to stay motivated with long-term treatment

6.2. Session 3: Converge

6.2.1 Confirmation of areas of full agreement

Prompt	Wording adjustment agreed	Confirmed (Y/N)
4. I want to know what psychological or emotional support is available to me		Y
6. I need help understanding my diagnosis and how it may affect my future and daily life		Y
9. I need a clear explanation of the benefits and possible side effects of my treatment	Benefits and side effected merged on the same prompt	Y
29. I want help coordinating care across different teams	"treatment" replaced by "care" to be more encompassing	Y
39. I need to understand the impact on intimacy with those closest to me		Y
8. I need to understand what are the direct and indirect costs linked to my condition	Direct and indirect costs reflected in the new wording	Y
10. I want my personal goals and values considered when choosing treatment	"Or" replaced by "And"	Y
43. I want to know how to access specialist care for my rare condition	"healthcare" replaced by "specialist care for my rare condition" to clarify the prompt	Y
31. I find it difficult to stay motivated with long-term treatment		Y

6.2.2 Discussion of disputed prompts

N.	Disputed prompt	Reasons – Group 1	Reasons – Group 2	Clarification / revision agreed
1	56. I need a simple calendar with dates and types of treatment	Group 1 discarded this prompt, as they felt that discussion of the calendar could naturally arise during the conversation prompted by Prompt 29 on care coordination. Also, this group considered that this type of calendar might be more important for non-surgical rare conditions than for surgical conditions.	Group 2 voted to include this prompt.	Participants agreed to discard this prompt from the Top 10 list, but refered it to the core working group for discussion on whether to include examples in prompt 29 that could include the need for a calendar. Concerns were raised by the lack of prompts on the Top 10 list that referred to self-management.

N.	Disputed prompt	Reasons – Group 1	Reasons – Group 2	Clarification / revision agreed
2	26. I need to understand how treatment decisions and changes are made when evidence is limited	Group 1 voted to include this prompt on the list because they agreed that evidence is usually limited for most rare and complex conditions, surgical and non-surgical, pediatric and adult onset.	Group 2 voted to discard this prompt with high convergence (7 votes out of 8). For Group 2, this is not the only prompt addressing the Trust domain. They considered that the prompt 72. "I find it difficult when different professionals give conflicting advice" also referred to trust. They proposed to include this dimension in prompt 29 (see cell below).	Participants agreed to include prompt 26 in the Top 10 list, citing Group 1's rationale that evidence is often limited for rare and complex conditions, whether surgical or non-surgical, and pediatric- or adult-onset. They also noted that, as the only prompt addressing the Trust domain, its inclusion was particularly important.
3	29. I want help coordinating care across different teams		Group 2 suggested replacing "teams" with "specialists" to clarify the prompt. Also proposed merging **Prompts 72 and 29** using this wording: *I want help coordinating treatments and/or conflicting advice*	Participants agreed to include prompt 29 in the Top 10 list and referred to the core team the decision on whether to include the provision of conflicting advice.

6.2.3 Final five-finger vote on the 10 prompts

Rules for consensus: Everyone at 3+: consensus. At least two-thirds at 3+ with some at 1–2: qualified approval; concerns recorded. Fewer than two-thirds: no agreement, referred to core group (not yet agreed).

The group reached consensus on the Top 10 list.

- Number of voters present: 14 (two participants had to leave before the vote due to travel schedules)
- 14 people voted 3 or higher: 5 people voted 5 (Strongly support), and 9 voted 4 (Support)

6.3. Summary and wrap-up

6.3.1 Agreed 10 prompts for the QPL

Of the 10 agreed final prompts for the QPL, 3 unchanged, 4 reworded, 2 combined (and reworded), 1 rescued from the bench (and reworded). All 10 were agreed by consensus in the final five-finger vote (14 voters: 5 strongly support, 9 support, none below 3).

Original ranking	Prompt (final wording)	Domain	Change type	Original wording	Rationale for change
14	4. I want to know what psychological or emotional support is available to me	Diagnosis and Treatment	Unchanged	–	–
2	6. I need help understanding my diagnosis and how it may affect my future and daily life	Diagnosis and Treatment	Reworded	6. I need help understanding how my diagnosis may affect my future and daily life	Makes room to discuss the diagnosis itself at length (symptoms, prognosis, full explanation), not only its impact (Mixed Group 1, Day 2)
6 / 8	9. I need a clear explanation of the	Diagnosis and Treatment	Combined (+ reworded)	9. I need a clear explanation of the possible	Overlap between benefits and side

	benefits and possible side effects of my treatment			side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention + 14. I want to discuss whether my treatment benefits outweigh the side effects	effects; patient group merged 9 and 14 and shortened the wording (Day 1). Clinicians also flagged side effects of not treating
17	29. I want help coordinating care across different teams	Diagnosis and Treatment	Reworded	29. I want help coordinating treatments across different teams	"Treatments" replaced by "care": a wider term, relevant beyond treatment discussions
4	39. I need to understand the impact on intimacy with those closest to me	Comprehensive-ness	Unchanged	–	–
n/a	8. I need to understand what are the direct and indirect costs linked to my condition	Diagnosis and Treatment	Rescued from bench (+ reworded)	8. I need to understand the costs related to my treatment I will have to cover	Rescued from the bench by the core group (June) and by agreement at the Day 1 wildcard (7 votes, below the 9-vote threshold); reworded to cover direct and indirect costs
3	10. I want my personal goals and values considered when choosing treatment	Diagnosis and Treatment	Reworded	10. I want my personal goals or values considered when choosing treatment	"Or" replaced by "and": goals and values are different things and both may need to be considered
19	43. I want to know how to access specialist care for my rare condition	Self-management and support	Reworded	43. I want to know how to access healthcare support	"Healthcare support" replaced by "specialist care for my rare condition" to clarify the meaning (patient group, Day 1)
5	31. I find it difficult to stay motivated with long-term treatment	Diagnosis and Treatment	Unchanged	–	–
15 / 12	26. I need to understand how treatment decisions and changes are made when evidence is limited	Diagnosis and Treatment / Trust	Combined (+ reworded)	26. I need to understand why changes are made to my treatment + 83. I want to understand how decisions are made when evidence is limited	Merged by Mixed Group 1 (Day 2): evidence is limited for most rare conditions (surgical and non-surgical, paediatric and adult onset); only prompt covering the Trust domain

6.3.2 Decisions on wording refinements

Original wording	Agreed wording	Rationale
6. I need help understanding how my diagnosis may affect my future and daily life	6. I need help understanding my diagnosis and how it may affect my future and daily life	Including more clearly the possibility of discussing again at length the diagnosis, symptoms and prognosis and getting a full explanation.
10. I want my personal goals or values considered when choosing treatment	10. I want my personal goals and values considered when choosing treatment	Clarity: values and objectives are different things, and both might need to be considered
26. I need to understand why changes are made to my treatment	26. I need to understand how treatment decisions and changes are made when evidence is limited	Combined with prompt 83
29. I want help coordinating treatments across different teams	29. I want help coordinating care across different teams	Care is a wider term and makes the prompt relevant not just for treatment discussions.

6.3.3 Items for core group review

No.	Type	Description	Source (day / group)
1	Wording	Discuss whether prompt 6 (impact in daily life and future) and prompt 8 on financial aspects could be merged	Day 2 – whole group
2	Wording	Discuss whether prompt 29 should include examples, including the calendar and whether to replace “team” by “specialists”. Discuss whether prompt 29 should include mention to conflicting advice (merged from prompt 72, only one in continuity) Review wording, proposal: *I want help coordinating care* ***and/or conflicting advice*** *across different* ***specialists***	Day 2 – whole group
3	Wording	Discuss how to merge prompts that refer to psychological and emotional support	Day 1 – Clinicians Group
4	Wording	Accessible wording and coherent formulation	Day 2 – Group 1
5	Content	Discuss whether the list should include more prompts that cover self-management aspects	Day 2 – Group 2
6	Content	Discuss whether the list should include 10 prompts or should include more	Day 1 - whole group
7	Design	Discuss what additional details should be included in the QPL document, such as date, name (of patient and specialist), etc.	Day 1 - whole group

7. LET IDEAS FLOW – NETWORKING SESSION

From priorities to actions, based on the priority themes emerging from the individual presentations at the Day 1 welcome session.

7.1. Champions' pitches

Champion	Theme	Idea(s) for action	Open question for the group
Anna Radová	The right to know Families as partners, clear information, shared decisions and a voice in research	Basic information about Usher Syndrome after diagnosis in all EU/EEA languages.	How to develop this.
Kate Tyler	Community, visibility and collective voice, and evidence-based healthcare Connecting care through lived experience, peer support and community	Enhance outreach to VACTERL patients (adults).	How to outreach patient populations out of the radar.
Katerina Papadopoulou	People-centred care Humanise care: psychologically informed, relationship-centred practice across the MDT	Communication training for healthcare facilities treating rare diseases. Appointment letters/waiting room posters / a gamifying app, facilitating patients to think of one personal question they want to ask in their consultation.	How to develop this.

7.2. Break-out outcomes and report-back

Priority / theme	1-to-2-year goal	Who is on board	How it works, first steps, format	Biggest risk / obstacle
The right to know	Basic information about Usher Syndrome after diagnosis in all EU/EEA languages	Marizela Kljajic provided a link to a Swedish rare disease information website with relevant information on Usher Syndrome – she was unsure whether this can be freely translated and reused, but it might be worth exploring the possibility of collaborating with the Swedish National Board of Health and Welfare (Socialstyrelsen) Anna will need to seek support from ERN EYE Anna could also seek support from Retina International (info@retina-International.org) and other patient organisations, e.g., Usher Initiative Austria (usher-syndrome@gmx.at)	How it works: The person delivering the diagnosis (geneticist?) provides a download link or gives a printout to the patient/caregiver. First steps: Expert clinicians/patient representatives review the Swedish website: use the applicable cross-border information (check copyright) and remove/adapt national-only information. Format: ERN EYE creates, translates, and uploads an online/printable leaflet/booklet containing, e.g.: • Incidence • Epidemiology / genetics • Symptoms • Psychological / social aspects • References • Contacts, links and resources (e.g., patient organisations)	Getting ERN EYE, Retina International and other patient organisations on board to develop the project (funding?) Getting clinicians to share the leaflet/booklet with patients/caregivers.

Priority / theme	1-to-2-year goal	Who is on board	How it works, first steps, format	Biggest risk / obstacle
Community, visibility and collective voice	Enhance outreach to VACTERL patients (adults)	Kate, Caroline, Nora, ERN eUROGEN (involve ERN LUNG, ERNICA)	Patient Organisation: • A peer support programme within the PO "Mentorship Programme" should include a psychologist to set and help maintain mentee/mentor boundaries. ERN level: • Propose creating a transversal ERN group (ERN LUNG, ERNICA, ERN eUROGEN, explore if more), as one doesn't seem to exist at the moment. Also, consider a joint webinar as a starting point. • Reaching out to clinicians in the ERNs to encourage peer patients attending their consultations to get in touch with Kate's PO (a raise-awareness campaign using the existing and excellent patient journey the ERN eUROGEN ePAG developed) EURORDIS • Community of Practice on Patient Representation • Explore podcast/interview/webinar formats	Funding, ERNs getting on board with the project, clinicians reaching out to patients at clinic level

Priority / theme	1-to-2-year goal	Who is on board	How it works, first steps, format	Biggest risk / obstacle
People-centred care	1. Communication training for healthcare professionals treating rare diseases, developed jointly across ERNs. 2. Appointment letters, waiting room posters or a gamified app to help patients think of one personal question they want to ask in their consultation.	Suggestions for who could be on board: ERN CRANIO psychology working group VASCERN psychology working group Patient representatives and clinicians from participating ERNs EURORDIS, which has already brought the CRANIO and VASCERN psychology working groups together ("Integrating mental health into European Reference Networks" 28 September 2026)	1.Training session First Steps: • Agree the approach within the ERN CRANIO psychology working group (develop a training on communication with healthcare professionals together with experts from other ERNs). • Contact VASCERN to propose developing a training course together, building on/adapting VASCERN's existing training on communication in consultations. Health professionals from other ERNs could be invited to join. • Once CRANIO and VASCERN clinicians agree on the content and approach, their coordinating teams take the proposal to other ERNs. • Develop with patient representatives and clinicians from those ERNs. Potential format of the training session: Short in-person or online training focused on practical skills that are easy to use in clinical practice, delivered by clinicians with experience in rare diseases. 2. Appointment letters and waiting room posters, etc. First Steps: • Start with small groups of patient representatives to learn what would help them, then return to the hospital to organise a trial of the letters, posters, or app.	Funding for developing the training and any later materials (letters, posters, app). Getting ERNs on board, including working out how cross-ERN working groups are set up. Clinicians' time and willingness to take part in training sessions and to answer patients' questions. Some patients may prefer a medical-only consultation and may find personal topics intrusive.

8. NEXT STEPS AND ACTIONS

No.	Action	Owner	Deadline
1	Compare results of consensus meeting with the initial Top 10 list rated and ranked by the panel and discuss if any changes are required.	Core working group	Q4 2026
2	Discuss whether prompt 6 (impact in daily life and future) and prompt 8 on financial aspects should be merged.	Core working group	Q4 2026
3	Discuss whether prompt 29 should include examples, including the calendar, rewording and potential merge with prompt 72.	Core working group	Q4 2026
4	Discuss how to merge prompts that refer to psychological and emotional support.	Core Working Group	Q4 2026
5	Discuss whether the list should include more prompts that cover self-management and continuity aspects.	Core Working Group	Q4 2026
6	Determine whether the QPL should consist solely of the 10 priority prompts or include these 10 prominently featured prompts alongside additional optional prompts.	Core Working Group	Q4 2026
7	Accessible wording and coherent formulation	EURORDIS	Q4 2026
8	Discuss more items to include in the design, such as the date and the names of the patient and the specialist.	Core Working Group	Q4 2026
9	Discuss instructions for patients and clinicians to be included in the final publication.	Core Working Group	Q4 2026

9. APPENDIX A. MASTER TRACKING OF ALL 32 PROMPTS

Rows in blue indicate the prompts that were categorised as the Top 10 by the panel rating and ranking rounds before the consensus workshop.

Top 20 – Prompt wording	Panel Rank	Wildcard D1 (21–32)	D1 Grp A (patients)	D1 Grp B (clinicians)	Final Status D2
Diagnosis and Treatment					
4. I want to know what psychological or emotional support is available to me	14		Included	x	Included
6. I need help understanding how my diagnosis may affect my future and daily life	2		Included	Included	Included
9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention	6		Included	Included	Included Reworded
10. I want my personal goals or values considered when choosing treatment	3		Included	Included	Included Reworded
14. I want to discuss whether my treatment benefits outweigh the side effects	8		x	x	Merged with 9
19. I need to know what will happen if I miss part of my treatment	10		x	x	x
22. I need clear guidance on what to do if I feel unwell during or after treatment	20		x	x	x
26. I need to understand why changes are made to my treatment	15		x	x	Included Reworded
29. I want help coordinating treatments across different teams	17		Included	Included	Included
31. I find it difficult to stay motivated with long-term treatment	5		x	Included	Included
Comprehensiveness					
33. I find it difficult talking to those close to me	7		x	x	x
34. I need help to put feelings into words	16		x	x	x
35. I want to ask for help but not sure who or how	13		x	x	x
38. I find it difficult not to feel overwhelmed by my symptoms	18		x	x	x
39. I need to understand the impact on intimacy with those closest to me	4		Included	x	Included
Self-management and support			x		
43. I want to know how to access healthcare support	19		Included	x	Included Reworded
56. I need a simple calendar with dates and types of treatment	1		Included	Included	x
62. I want to discuss my hopes and what a realistic outcome from treatment could be	11		x	x	x
Continuity					
72. I find it difficult when different professionals give conflicting advice	9			Included	x
Trust					
83. I want to understand how decisions are made when evidence is limited	12		Included	x	Merged with 26

Prompts “on the bench” 21-32	Panel Rank	Wildcard Day 1 - result
Diagnosis and Treatment		
21. I find it difficult to tell if my symptoms are because of my condition or a side effect of my treatment	25	no
25. I struggle to express myself during appointments. I find discussing my treatment intimidating and don't know how to express myself fully or properly	21	no
32. I want support to adjust my treatment as my life circumstances may change	30	no
8. I need to understand the costs related to my treatment I will have to cover	Rescued by core team in June	Included. Yes, new wording proposed: I need to understand what are the direct and indirect costs linked to my condition
Comprehensiveness		
37. I find it difficult to look ahead. I need support to help me feel more confident about the future.	28	no
Self-management and support		
52. I need someone to explain my treatment to me in words I understand.	29	no
53. I need to know what my treatment is supposed to do.	27	no
58. I find it difficult to understand if my certain wellbeing needs are covered by my treatment plan	26	no
Continuity		
66. I need my GP to understand my condition	23	no
64. I want to understand who is responsible for coordinating my care to ensure that all the doctors involved are kept up to date with my overall health needs	Rescued by core team	
Trust		
82. I want to know if there are any patient versions of national medical guidelines for my condition	22	no
85. My current treatment does not feel right for me. I need us to discuss other treatment options	24	no

10.APPENDIX B. SUMMARY OF PROMPT STATUS

Table 1: Overview of 20 (+ 1 rescued) prompts by domain

- Diagnosis and Treatment: 7 of its 10 prompts were kept, and 14 was included as part of 9; only 19 and 22 were discarded. This domain now makes up most of the final list.
- Comprehensiveness: 4 of its 5 prompts (33, 34, 35, 38) were discarded, all from the psychological cluster, so only 39 on intimacy remains, unless the group folds those prompts into prompt 4.
- Self-management and support: Only 43 was kept; the panel's top-ranked prompt (56) and prompt 62, which overlapped with 10, were discarded.
- Continuity has no prompt left after 72 was discarded.
- Trust: one prompt was kept through the merge of prompt 83 into 26.

Coloured cells identify the agreed wording.

Domain	Orig. rank	Original wording	Decision	New wording	Reason
Diagnosis and Treatment	14	4. I want to know what psychological or emotional support is available to me	Kept unchanged	-	0 discard votes in both mixed groups on Day 2 (clinicians had 5 discard votes on Day 1)
	2	6. I need help understanding how my diagnosis may affect my future and daily life	Kept reworded	6. I need help understanding my diagnosis and how it may affect my future and daily life	Near-unanimous support (0–1 discard votes in every round); reworded to include the diagnosis itself
	6	9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention	Kept reworded	9. I need a clear explanation of the benefits and possible side effects of my treatment	0 discard votes on Day 2; combined with P14 to cover benefits and side effects together
	3	10. I want my personal goals or values considered when choosing treatment	Kept reworded	10. I want my personal goals and values considered when choosing treatment	Kept over the overlapping P62; "or" → "and"
	8	14. I want to discuss whether my treatment benefits outweigh the side effects	Merged with 9	-	Overlap with P9; merged by the patient group on Day 1 (clinicians: 8 of 9 voted to discard)
	10	19. I need to know what will happen if I miss part of my treatment	Discarded	-	Strongest convergence to discard (clinicians 9 of 9 on Day 1; 6–7 per group on Day 2)
	20	22. I need clear guidance on what to do if I feel unwell during or after treatment	Discarded	-	High discard votes (clinicians 8 of 9 on Day 1; 7 per group on Day 2)

	15	26. I need to understand why changes are made to my treatment	Kept reworded	26. I need to understand how treatment decisions and changes are made when evidence is limited	Evidence is limited for most rare conditions (surgical and non-surgical, paediatric and adult onset); merged with P83, the only Trust prompt. Group 2 had voted to discard it (7 of 8)
	17	29. I want help coordinating treatments across different teams	Kept reworded	29. I want help coordinating care across different teams	Included by every group; "treatments" → "care"; further wording referred to core group
	5	31. I find it difficult to stay motivated with long-term treatment	Kept unchanged	-	Linked to treatment adherence (Mixed Group 2); Group 2 merged 29 and 72 to make room for it
	n/a	8. I need to understand the costs related to my treatment I will have to cover	Rescued, kept reworded	8. I need to understand what are the direct and indirect costs linked to my condition	Not in the Top 20: rescued by the core group (June) and by agreement at the Day 1 wildcard (7 of 16 votes); reworded to cover direct and indirect costs
Comprehensiveness	7	33. I find it difficult talking to those close to me	Discarded	-	High discard votes in every round (Day 2: 7 and 8). Clinicians proposed one prompt covering psychological aspects (4, 33, 35, 39); referred to core group
	16	34. I need help to put feelings into words	Discarded	-	High discard votes (clinicians 8 of 9 on Day 1; Group 2 8 of 8 on Day 2); psychological cluster
	13	35. I want to ask for help but not sure who or how	Discarded	-	High discard votes (Day 2: 6 and 8); part of the psychological cluster the core group will consider merging into P4
	18	38. I find it difficult not to feel overwhelmed by my symptoms	Discarded	-	High discard votes (Day 1: clinicians 9 of 9, patients 6 of 7)
	4	39. I need to understand the impact on intimacy with those closest to me	Kept unchanged	-	Patients stressed that intimacy is hard to raise in consultations; both mixed groups kept it (0–2 discard votes)
Self-management and support	19	43. I want to know how to access healthcare support	Kept reworded	43. I want to know how to access specialist care for my rare condition	Reworded on Day 1 to clarify its meaning, after which support grew (Group 2: 1 discard vote)
	1	56. I need a simple calendar with dates and types of treatment	Discarded	-	Mixed Group 1: the calendar would come up under P29 (care coordination) and matters more for non-surgical conditions (surgical/non-surgical balance). Group 2 kept it. Plenary discarded it but

					referred the “example in P29” idea to the core group; concern noted about lack of self-management prompts
	11	62. I want to discuss my hopes and what a realistic outcome from treatment could be	Discarded	-	Overlap with P10; clinicians chose P10 over P62 on Day 1 and Group 2 saw the same overlap on Day 2
Continuity	9	72. I find it difficult when different professionals give conflicting advice	Core Team to decide if merging with prompt 29	-	Group 2 saw it as a Trust issue and proposed merging into P29 (“…and/or conflicting advice”); referred to core group
Trust	12	83. I want to understand how decisions are made when evidence is limited	Merged with prompt 26	-	Only prompt covering the Trust domain; combined with P26 by Mixed Group 1 on Day 2

Table 2: Overview of original 20 prompts by panel ranking

Of the original Top 20, 9 were kept (3 unchanged, 6 reworded, of which 2 absorbed another prompt), 2 were merged into other prompts (14 → 9; 83 → 26) and 9 were discarded (19, 22, 33, 34, 35, 38, 56, 62, 72). Prompt 8, rescued from the bench, completes the final 10. Five prompts (33, 35, 38, 56, 72) remain open for possible merging by the core group.

Colour key: Kept unchanged (green); Kept reworded (yellow); Merged (blue); Discarded (grey); Rescued (purple)

Orig. rank	Original wording	Decision	Reason	Domain
1	56. I need a simple calendar with dates and types of treatment	Discarded	Mixed Group 1: the calendar would come up under P29 (care coordination) and matters more for non-surgical conditions (surgical/non-surgical balance). Group 2 kept it. Plenary discarded it but referred the “example in P29” idea to the core group; concern noted about lack of self-management prompts	Self-management and support
2	6. I need help understanding how my diagnosis may affect my future and daily life	Kept reworded	Near-unanimous support (0–1 discard votes in every round); reworded to include the diagnosis itself	Diagnosis and Treatment
3	10. I want my personal goals or values considered when choosing treatment	Kept reworded	Kept over the overlapping P62; “or” → “and”	Diagnosis and Treatment
4	39. I need to understand the impact on intimacy with those closest to me	Kept unchanged	Patients stressed that intimacy is hard to raise in consultations; both mixed groups kept it (0–2 discard votes)	Comprehensiveness
5	31. I find it difficult to stay motivated with long-term treatment	Kept unchanged	Linked to treatment adherence (Mixed Group 2); Group 2 merged 29 and 72 to make room for it	Diagnosis and Treatment
6	9. I need a clear explanation of the possible side effects of my treatment, including which side effects are normal, which ones I should monitor, and which are serious or require urgent medical attention	Kept reworded	0 discard votes on Day 2; combined with P14 to cover benefits and side effects together	Diagnosis and Treatment

7	33. I find it difficult talking to those close to me	Discarded	High discard votes in every round (Day 2: 7 and 8). Clinicians proposed one prompt covering psychological aspects (4, 33, 35, 39); referred to core group	Comprehensiveness
8	14. I want to discuss whether my treatment benefits outweigh the side effects	Merged	Overlap with P9; merged by the patient group on Day 1 (clinicians: 8 of 9 voted to discard)	Diagnosis and Treatment
9	72. I find it difficult when different professionals give conflicting advice	Core Team to decide if merging with prompt 29	Group 2 saw it as a Trust issue and proposed merging into P29 ("…and/or conflicting advice"); referred to core group	Continuity
10	19. I need to know what will happen if I miss part of my treatment	Discarded	Strongest convergence to discard (clinicians 9 of 9 on Day 1; 6–7 per group on Day 2)	Diagnosis and Treatment
11	62. I want to discuss my hopes and what a realistic outcome from treatment could be	Discarded	Overlap with P10; clinicians chose P10 over P62 on Day 1 and Group 2 saw the same overlap on Day 2	Self-management and support
12	83. I want to understand how decisions are made when evidence is limited	Merged	Only prompt covering the Trust domain; combined with P26 by Mixed Group 1 on Day 2	Trust
13	35. I want to ask for help but not sure who or how	Discarded	High discard votes (Day 2: 6 and 8); part of the psychological cluster the core group will consider merging into P4	Comprehensiveness
14	4. I want to know what psychological or emotional support is available to me	Kept unchanged	0 discard votes in both mixed groups on Day 2 (clinicians had 5 discard votes on Day 1)	Diagnosis and Treatment
15	26. I need to understand why changes are made to my treatment	Kept reworded	Evidence is limited for most rare conditions (surgical and non-surgical, paediatric and adult onset); merged with P83, the only Trust prompt. Group 2 had voted to discard it (7 of 8)	Diagnosis and Treatment
16	34. I need help to put feelings into words	Discarded	High discard votes (clinicians 8 of 9 on Day 1; Group 2 8 of 8 on Day 2); psychological cluster	Comprehensiveness
17	29. I want help coordinating treatments across different teams	Kept reworded	Included by every group; "treatments" → "care"; further wording referred to core group	Diagnosis and Treatment
18	38. I find it difficult not to feel overwhelmed by my symptoms	Discarded	High discard votes (Day 1: clinicians 9 of 9, patients 6 of 7)	Comprehensiveness
19	43. I want to know how to access healthcare support	Kept reworded	Reworded on Day 1 to clarify its meaning, after which support grew (Group 2: 1 discard vote)	Self-management and support
20	22. I need clear guidance on what to do if I feel unwell during or after treatment	Discarded	High discard votes (clinicians 8 of 9 on Day 1; 7 per group on Day 2)	Diagnosis and Treatment
n/a	8. I need to understand the costs related to my treatment I will have to cover	Rescued, kept reworded	Not in the Top 20: rescued by the core group (June) and by agreement at the Day 1 wildcard (7 of 16 votes); reworded to cover direct and indirect costs	N/A

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