

	First wave							Second wave					Third wave		
	P01	P03	P02	P06	P04	P07	P05	P08	P12	P09	P13	P11	P10	P15	P14
Theme 1: Disease and patient selection decisions															
Collective decision-making as an approach to selecting	new				x					x				x	
Disease progression as selection criteria				new	x			x	x	x		x			
Emotions and subjectivity as a factor				new	x					x		x		x	
Family members' expectations and knowledge as selection criteria			new	x		x	x			x					
Prevalence as selection criteria	new			x		x	x	x	x	x			x		
Rationality and pragmatism in selection	new				x	x	x	x	x	x			x		
Severity as selection criteria				new	x	x			x	x		x	x		
Theme 2: Patient communication and managing expectations															
Balancing hope and realism	new	x	x	x	x	x	x		x	x		x	x	x	x
Education and scientific literacy	new	x	x	x	x	x	x	x	x	x		x	x	x	
External influences on patient expectations	new			x	x		x				x		x	x	
How and when to initiate contact	new	x	x	x	x	x	x	x		x	x			x	
Ongoing communication and feedback to patients	new	x		x		x	x		x	x	x			x	x
Relational dynamic between researchers and participants	new	x		x	x	x	x		x		x	x		x	x

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Theme 3: Factors defining therapy value															
Burden and Benefit of Treatment Modalities				new	x	x	x	x	x				x	x	x
Moral obligation to treat or to act	new	x	x	x											
Individual vs. Broader (Societal) Benefit	new	x		x	x	x	x	x	x			x	x		
Perceived Value and Interpretation of Treatment Impact	new			x	x	x	x	x	x	x	x	x	x	x	
Treating vs Non-treating	new		x					x		x	x				
Uncertainty in Therapy Outcome	new	x		x	x	x			x	x	x	x	x	x	x
Theme 4: Explicit and hidden barriers in therapy accessibility															
Collaboration with industry	new							x				x	?	x	
Education and advocacy impact on access	new							x							
Fair access as responsibility of others								new					x		
Financial pressure on vulnerable people	new				x			x	x		x		x		
Geographic and socioeconomic factors in access to therapy	new			x	x			x			x		x		
High costs as an access factor	new			x	x			x			x				
Long-term financial impact for healthcare system	new	x			x			x				x			
Scaling and infrastructure challenges	new	x	x					x	x			x			x
Sustainable reimbursement models	new				x			x		x			x		
Technological advancements to impact the costs	new		x		x			x			x				