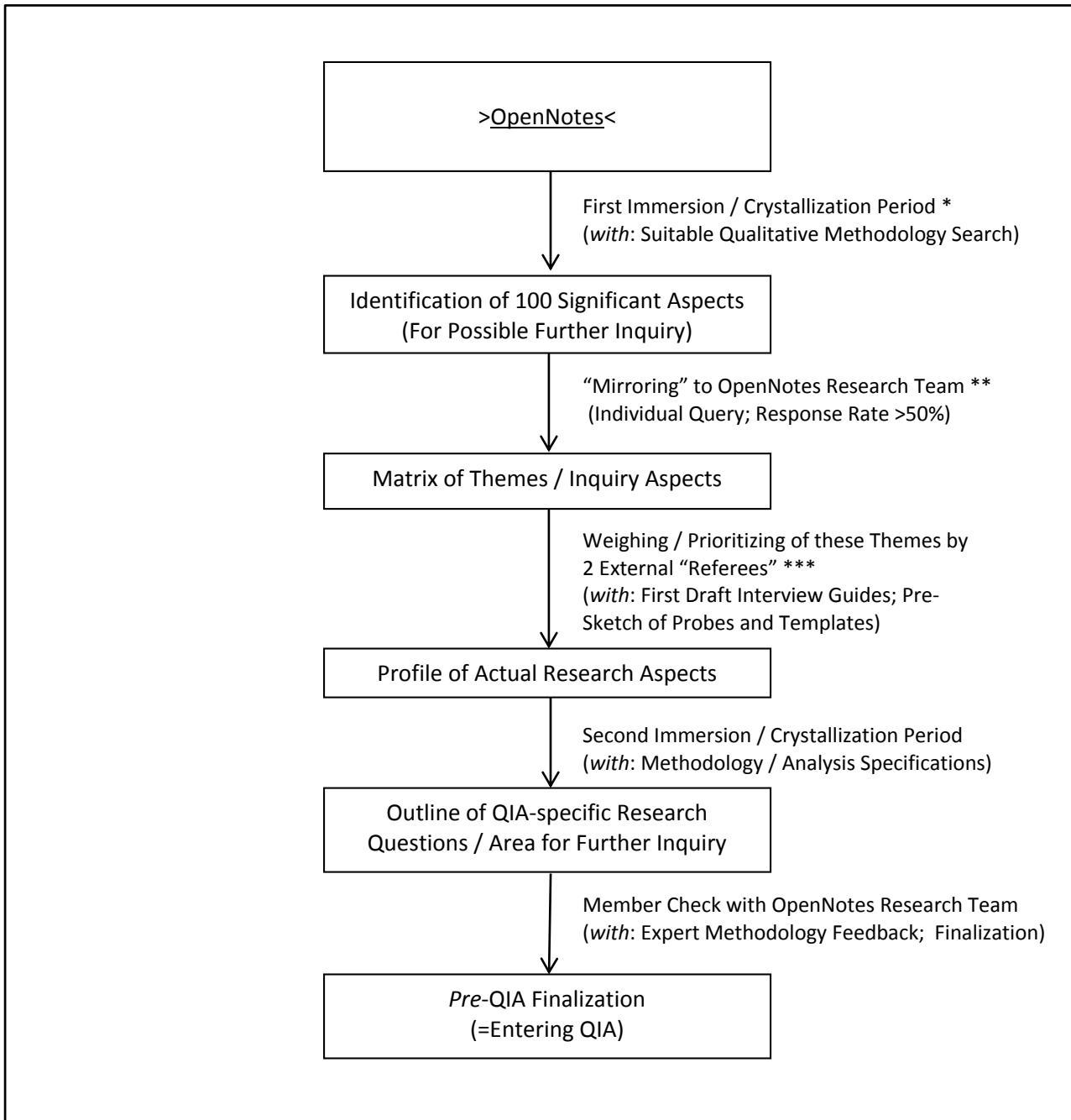


Appendices

Appendix 1 [Figure]: Pre-QIA Study Immersion Project – *Project Flow (Iterative Cycles)*



* Following comprehensive literature search in the field, and field observations, conversations with qualified scholars [colloquy] and with OpenNotes participating physicians, as well as non-participating physicians and patients

** “Colleague inquiry” (study team survey)

*** Independent of OpenNotes team, knowledgeable; expert 1: patient perspective (PharmD), expert 2: physician perspective (MD)

Abbreviations: QIA= Qualitative Interview Analysis

Appendix 2 [Table]: Free Text Questions in OpenNotes Patient Questionnaires (Surveys)

Baseline Survey Questions	
Text in Q.18	"If you have any comments about being able to read your visit notes online, please write them here:"
Text in Q.40	"If there is anything else that you would like us to know about you, or other comments you would like to make, please write them here:"
Post Survey Questions	
Text in Q.4	"Please tell us more about why you didn't read your doctor's notes."
Text in Q.18	"Please briefly tell us how you used your notes. We would appreciate any examples you have to help us understand."
Text in Q.32	"Did something happen as a result of reading your notes?"
Text in Q.54	"Do you have any other changes or suggestions about open notes?"
Text in Q.60	"Is there anything else that you would like us to know about you, or other comments you would like to make, please write them here."

Appendix 3 [Table]: Codebook (FTA)

Theme (No.)	Theme	Subtheme (Code)	Code (No.)	Sentiment	Focus	Examples / Quotes (with reference number = no. of patient comment/statement)
A	UNDERSTANDING	understanding (and appreciating) doctor's work, skills	A1	+	PCP	"[Reading the notes] reinforced my already great appreciation for my doctor's caring and skills" (164)
		understanding processes and (doctor's) plan; understanding doctor's 'thinking'	A2	+	PCP	"[I used the notes] to gauge my doctor's thoughts after-the-fact" (221)
		understanding one's own health information	A3	+	PAT	"It does help me understand better what is going on with my health" (173)
		refreshing memory (of visit)	A4	+	PAT	"Sometimes I can't remember everything we spoke about, so the notes come in handy" (176)
		reassuring, confirmation (of patient's understanding)	A5	+	PAT	"[I used them to] confirm my understanding of his instructions and advice" (262)
		helping others to understand (e.g., share of understanding)	A6	+	BON	"The notes [...] allow my family to understand" (296)
		making sure doctor understands patient	A7	+	PCP	"I used the notes to make sure my Dr. understands me" (172)
		detecting different perceptions (e.g., of what is important; of patient's needs)	A8	+	BON	"[Notes were] clearing up perceived differences in what occurred in the office visit" (477)
		detecting mistakes, due to misunderstanding	A9	+	BON	"I discovered that the doctor had misunderstood something I said" (203)
		lack of non-verbal communication (possible consequences: worries, fear of misunderstanding)	A10	-	PAT	"The emphasis of a word or phrase is not conveyed so there can be angst created when reading the notes" (137)
		language, terminology difficulties	A11	-	PAT	"Certain terms may not be understood by 'laymen'" (63)
		more confusion [anxiety, worries] (due to impaired/lack of understanding, or actual note content)	A12	-	PAT	"What is written [...] can be very confusing or alarming to patients" (16)
		less confusion [anxiety, worries] (due to improved/clear understanding)	A13	+	PAT	"It saves my being confused and unsure" (37)
		learning opportunity (educational: patient more knowledgeable, well-informed; better prepared)	A14	+	PAT	"I view this option as an excellent learning opportunity" (85)
		B	RELATIONSHIP	trust (sign of; elicitation, enhancement thereof)	B1	+
connection - between visits (bridging, bonding of information and communication participants)	B2			+	BON	"I can plug into [the notes] as needed in between my office visits – I think that is a very valuable" (273)
patient perceives/experiences ongoing (steady) support	B3			+	PAT	"The notes are experienced as being another level of my doctor's ongoing support" (273)
open and transparent communication (experience)	B4			+	BON	"Reading his notes confirmed to me that he was not holding anything back" (348)
better communication (overall; interactivity)	B5			+	BON	"Communication improves markedly" (381)
partnership ('same page'; share 'in' information)	B6			+	BON	"I am able to work with my doc as a partner" (353)
participation, patient as a 'team member'; collaboration/collaborator in care	B7			+	PAT	"I think this is a wonderful idea and allows the patient to be a [...] member of the team" (39)
relationship strengthened (also: better mutual 'understanding' - sympathy, empathy)	B8			+	BON	"Having the notes available has strengthened the relationship between my primary care doctor and myself" (363)
needs of patient addressed, (better) met	B9			+	PAT	"[Notes enable patient] to address needs that might arise without having to make separate appointments" (115)
doctor as 'policeman' (coordinator, safe-guard for patient)	B10			+	PCP	"I realized that [...] the PCP was like a policeman directing traffic" (336)
increased confidence (notes put patient at ease, reduce anxiety; feeling of security, being well-cared for)	B11			+	PAT	"Reading the notes made me feel more confident in my Drs." (355)
patient's curiosity satisfied (gets insight; 'no' secrets)	B12			+	PAT	"Satisfied my curiosity" (245)
threatened when inaccuracies occur (are perceived)	B13			-	BON	"[The error] is still in that report that others read, despite my protests" (424)
fear of/concern over putting extra strain/burden on doctor's (staff) time budget, work flow, resources	B14			-	PCP	"Concerned about extra work this would make for MD" (96)
C	QUALITY			informed, participating patients use less of doctor's (practice) resources	B15	+
		coordination: coordination of health information and care (e.g., managing complex cases; information integration)	C1	+	PCP	"Open Notes [...] help in coordination between specialist" (433)
		information transfer: flow of information, exchangeability, general mobility and permeability; easier to share, discuss	C2	+	PAT	"I had it in writing for extended family to see also" (301)
		access: keeping health information for patients accessible and available (ease of access); lowering threshold, barriers	C3	+	PAT	"The notes are put in system and always available if needed" (303)
		transparency (as standard or requirement, quality indicator); information not exclusive, restricted (knowledge sharing)	C4	+	PAT (BON)	"The more good information, the better" (61); "this [...] only adds to the quality of my health care" (85)
		ownership of notes (health information): sign of and advocacy for patient or consumer rights	C5	+	PAT	"I have a right to know, good or bad" (382)
		patient protection: safety, confidentiality and privacy concerns	C6	-/o	PAT	"I am concerned about breach of privacy" (45)
		record: keeping track of health information (chronicle, summary); notes as reference, ('complete') overview	C7	+	PAT	"The notes [...] now keep a running chronicle for me" (252)
		staying up-to-date ('tuned') with care, health information	C8	+	PAT	"Reading the notes kept me abreast of what was happening" (412)
		clarity of information: general sign and facilitator of clarity	C9	+	BON	"I feel it attributes to a much clearer and concise form of health care" (462)
		clarity of health information: adherence and compliance facilitated; e.g., due to clear instructions, medication (etc.)	C10	+	PAT	"It [...] sometimes clarifies my need and use of medications" (191)
		clarity of information: concerns over lack of it (e.g., too confusing or too much of information, lack of critical facts)	C11	-	PAT	"The visit notes might be too much information in a form we can't appropriately process" (46)
		concerns about fragmentation, incompleteness or poor coordination (disintegration) of notes/health information	C12	-	PCP (BON)	"I often receive conflicting answers (in notes) even from people within the same department" (564)
		concerns about candor, veracity/truthfulness, accuracy, and reliability of notes (when opened); e.g., 'filtering' by doctor?	C13	-	PCP	"I think that it might inhibit the doctor's ability to write frankly" (57)
		quality of documentation: error avoidance (procedural); 'quality check' of doctor by patient ('double-checking')	C14	+	PCP	"The biggest benefit I see is being able to [...] double check" (66)
D	SELF-CARE	efficiency: using time and other resources more efficiently	C15	+	PCP (BON)	"I feel it [...] will continue to help me use the time I spend with my [primary care physician] more effectively" (552)
		generally facilitating self-engagement and involvement; patient activation and empowerment	D1	+	PAT	"It allows me [...] to be more active in my treatments" (296); "I feel that I am more involved with my care" (351)
		reinforcing self-care and self-management skills, abilities to self-coordinate, to function on his/her own	D2	+	PAT	"I feel better equipped" (302); "I feel more sympathetic about having to coordinate my care myself" (375)
		motivation (e.g., for making and/or keeping healthy lifestyle changes; for complying with agreements or shared advice)	D3	+	PAT	"Being able to read his notes [...] has motivated me to lose weight and watch what I eat" (184)
		patient-centeredness (sign of; tool for); patient has a proactive and part-taking role	D4	+	PAT	"It made me feel [...] proactive [...] and not just reacting" (210)
		control: patient feels more in control; reduced helplessness	D5	+	PAT	"The notes [...] gave me better ways to cope with many of the difficulties I face" (344)
		active encouragement (e.g., to continue taking care of oneself, or reflect upon/prepare visits, ask self-reliant questions)	D6	+	PAT	"Having [...] notes available [...] helped to guide and inform new questions in each visit" (299)
		notes serve to monitor health and self-care options	D7	+	PAT	"It [shows] [...] what actions I can take to improve my health" (37)
E	FUTURE REFINEMENT (IMPROVEMENTS)	patients less challenged, distracted during visit: can work over their health information at home (themselves, with s.o.)	D8	+	PAT	"By reading the notes I was able to study them at length in the privacy of my home" (225)
		sustainability: providing resources, allocating financial funds, or capital; keep this ('extra?') service/make it permanent	E1	o(+)	BON	"I hope that after the study that it will become permanent!!!" (86)
		including (involving) specialists; more/all' doctors (providers) should participate	E2	o(+)	PCP	"More of my Doctor's should put notes on-line for me" (289)
		offering online dictionary/lexicon, or glossary (tool-box); add standard explanations, FAQs, etc.	E3	o(+)	PAT	"I have sometimes wished I could easily access a 'dictionary' of medical abbreviations used" (422)
		patient can add/comment/approve/work on note; possibly: joint notes (note preparation); continuous, shared document	E4	o(+)	PAT (BON)	"I like the idea of adding my own comment" (433)
		different types and categories of notes	E5	o(+)	BON	"I would suggest having different categories of notes" (113)
		[explicit statement: 'continue as it is' - changes/suggestions for improvement negated] [difficulties accessing/finding notes (reason unclear)]	E6 E7	+ -(o)	PAT (BON) PAT	"OpenNotes is perfect the way it is" (420) "I looked everywhere but could not find any notes available" (139)

Abbreviations: PAT= patient; PCP= primary care physician; BON= both or neutral (other)

Appendix 4 [Table]: Quantitative Descriptive Analysis (FTA)

Themes / Codes	Imported Survey Data (N=576)	Baseline (n=138)	Post (n=438)	Low-User (n=39)	High-User (n=537)	Female (n=414)	Male (n=162)	MH Condit+ (n=175)	MH Condit- (n=401)	Age Cat A [‘young’] (n=278)	Age Cat B [‘old’] (n=298)	College+ (n=357)	College- (n=218)	White (n=509)	Non-White (n=61)	SRH/P- E/VG (n=158)	SRH/P- G/OK (n=187)	SRH/P- F/P (n=186)	SRH/B- E/VG (n=128)	SRH/B- G/OK (n=180)	SRH/B- F/P (n=172)	
A UNDERSTANDING																						
a01: understanding (and appreciating) doctor’s work, skill	6.1%	5.8%	6.2%	2.6%	6.3%	7.5%	2.5%	5.1%	6.5%	6.5%	5.7%	7.8%	3.2%	6.1%	6.6%	6.3%	8.6%	3.8%	11.7%	6.1%	4.7%	
a02: understanding processes and (doctor’s) plan; understand	8.0%	5.1%	8.9%	5.1%	8.2%	7.2%	9.9%	9.7%	7.2%	9.0%	7.0%	8.7%	6.9%	8.3%	6.6%	5.1%	10.7%	9.1%	6.3%	9.4%	8.7%	
a03: understanding one’s own health information	13.2%	13.0%	13.2%	10.3%	13.4%	13.5%	12.3%	9.1%	15.0%	14.7%	11.7%	13.7%	12.4%	13.2%	13.1%	10.1%	17.1%	11.8%	15.6%	11.7%	12.8%	
a04: refreshing memory (of visit)	17.0%	12.3%	18.5%	12.8%	17.3%	19.1%	11.7%	17.7%	16.7%	21.2%	13.1%	14.3%	21.6%	16.9%	16.4%	20.3%	16.0%	18.3%	17.2%	16.7%	13.4%	
a05: reassuring, confirmation (of patient’s understanding)	15.8%	7.2%	18.5%	7.7%	16.4%	15.9%	15.4%	16.0%	15.7%	18.7%	13.1%	13.2%	20.2%	16.1%	13.1%	18.4%	17.1%	15.6%	18.8%	16.1%	14.0%	
a06: helping others to understand (e.g., share of understand	1.6%	0.7%	1.8%	0.0%	1.7%	1.9%	0.6%	1.1%	1.7%	1.4%	1.7%	1.7%	1.4%	1.8%	0.0%	0.6%	1.1%	3.2%	1.6%	0.0%	1.7%	
a07: making sure doctor understands patient	8.9%	8.7%	8.9%	0.0%	9.5%	8.5%	9.9%	14.3%	6.5%	9.4%	8.4%	9.0%	8.7%	9.0%	8.2%	7.0%	11.8%	8.6%	7.8%	10.6%	8.7%	
a08: detecting different perceptions (e.g., of what is impo	1.9%	0.0%	2.5%	2.6%	1.9%	1.7%	2.5%	4.0%	1.0%	1.8%	2.0%	1.4%	2.8%	2.0%	1.6%	1.3%	1.6%	3.2%	1.6%	1.7%	2.9%	
a09: detecting mistakes, due to misunderstanding	4.0%	2.2%	4.6%	5.1%	3.9%	3.9%	4.3%	6.3%	3.0%	4.0%	4.0%	5.0%	2.3%	4.3%	1.6%	3.2%	4.8%	4.3%	5.5%	2.8%	5.8%	
a10: lack of non-verbal communication (possible consequ	1.4%	2.2%	1.1%	0.0%	1.5%	1.4%	1.2%	1.7%	1.2%	2.2%	0.7%	1.7%	0.9%	1.4%	0.0%	1.9%	1.6%	0.5%	2.3%	1.1%	1.2%	
a11: language, terminology difficulties	2.4%	4.3%	1.8%	2.6%	2.4%	2.7%	1.9%	2.3%	2.5%	1.8%	3.0%	2.8%	1.8%	2.6%	0.0%	5.1%	2.1%	0.5%	3.9%	1.7%	2.3%	
a12: more confusion [anxiety, worries] (due to impaired/	3.6%	8.7%	2.1%	12.8%	3.0%	3.6%	3.7%	1.1%	4.7%	4.3%	3.0%	4.5%	2.3%	3.7%	1.6%	4.4%	3.2%	2.7%	5.5%	3.9%	2.9%	
a13: less confusion [anxiety, worries] (due to improved/c	5.0%	5.1%	5.0%	5.1%	5.0%	5.3%	4.3%	6.3%	4.5%	5.4%	4.7%	4.2%	6.4%	5.3%	3.3%	2.5%	5.9%	7.0%	4.7%	3.9%	7.0%	
a14: learning opportunity (educational; patient more kno	7.6%	5.8%	8.2%	7.7%	7.6%	8.7%	4.9%	5.1%	8.7%	7.2%	8.1%	7.3%	8.3%	8.4%	0.0%	7.0%	9.6%	6.5%	7.0%	5.6%	8.7%	
B RELATIONSHIP																						
b01: trust (sign of; elicitation, enhancement thereof)	9.0%	5.1%	10.3%	2.6%	9.5%	10.6%	4.9%	8.6%	9.2%	8.6%	9.4%	10.1%	7.3%	8.4%	14.8%	6.3%	10.2%	11.3%	11.7%	7.2%	11.0%	
b02: connection - between visits (bridging, bonding of in	2.4%	4.3%	1.8%	2.6%	2.4%	2.4%	2.5%	2.3%	2.5%	2.2%	2.7%	2.0%	3.2%	2.4%	1.6%	1.9%	2.1%	1.6%	1.6%	4.4%	1.7%	
b03: patient perceives/experiences ongoing (steady) sup	3.6%	4.3%	3.4%	5.1%	3.5%	3.9%	3.1%	4.6%	3.2%	4.7%	2.7%	3.1%	4.6%	3.1%	6.6%	2.5%	3.7%	4.3%	4.7%	2.8%	4.7%	
b04: open and transparent communication (experience)	3.5%	4.3%	3.2%	7.7%	3.2%	3.4%	3.7%	2.3%	4.0%	2.9%	4.0%	3.9%	2.8%	3.5%	3.3%	3.8%	5.3%	2.2%	3.1%	6.1%	2.3%	
b05: better communication (overall); interactivity)	7.3%	10.1%	6.4%	10.3%	7.1%	7.0%	8.0%	13.1%	4.7%	6.8%	7.7%	8.4%	5.5%	7.9%	3.3%	7.6%	10.2%	3.2%	8.6%	8.9%	7.0%	
b06: partnership (‘same page’; share ‘in’ information)	4.3%	4.3%	4.3%	5.1%	4.3%	3.9%	5.6%	5.1%	4.0%	2.9%	5.7%	3.9%	5.0%	4.5%	1.6%	4.4%	4.8%	2.7%	4.7%	5.6%	4.1%	
b07: participation, patient as a ‘team member’; collabora	3.1%	2.9%	3.2%	5.1%	3.0%	2.7%	4.3%	3.4%	3.0%	2.5%	3.7%	3.4%	2.8%	3.3%	1.6%	3.8%	2.7%	1.6%	4.7%	2.8%	4.1%	
b08: relationship strengthened (also: better mutual ‘und	7.6%	5.8%	8.2%	2.6%	8.0%	8.2%	6.2%	8.0%	7.5%	8.3%	7.0%	8.7%	6.0%	7.3%	11.5%	5.7%	9.1%	8.1%	8.6%	8.3%	8.1%	
b09: needs of patient addressed, (better) met	2.4%	3.6%	2.1%	0.0%	2.6%	2.9%	1.2%	3.4%	2.0%	3.2%	1.7%	2.8%	1.8%	2.4%	3.3%	1.3%	2.7%	3.8%	1.6%	2.2%	4.7%	
b10: doctor as ‘policeman’ (coordinator, safe-guard for p	1.4%	1.4%	1.4%	2.6%	1.3%	1.2%	1.9%	0.6%	1.7%	1.1%	1.7%	2.0%	0.5%	1.6%	0.0%	0.0%	0.5%	3.2%	0.8%	0.6%	3.5%	
b11: increased confidence (notes put patient at ease, red	7.6%	4.3%	8.7%	10.3%	7.4%	9.2%	3.7%	8.6%	7.2%	9.4%	6.0%	8.4%	6.4%	6.7%	14.8%	5.7%	10.7%	7.5%	10.2%	5.0%	8.7%	
b12: patient’s curiosity satisfied (gets insight; ‘no’ secret	3.1%	2.2%	3.4%	7.7%	2.8%	3.4%	2.5%	2.3%	3.5%	3.6%	2.7%	2.8%	3.7%	2.8%	4.9%	5.7%	3.7%	1.1%	3.9%	3.9%	1.2%	
b13: threatened when inaccuracies occur (are perceived)	3.6%	4.3%	3.4%	5.1%	3.5%	4.1%	2.5%	2.3%	4.2%	3.2%	4.0%	4.8%	1.8%	3.9%	1.6%	4.4%	0.5%	4.8%	5.5%	2.2%	4.7%	
b14: fear of/concern over putting extra strain/burden on	5.4%	11.6%	3.4%	5.1%	5.4%	6.3%	3.1%	2.9%	6.5%	6.5%	4.4%	7.0%	2.8%	5.7%	3.3%	7.0%	4.3%	3.8%	6.3%	3.9%	7.6%	
b15: informed, participating patients use less of doctor’s	2.6%	3.6%	2.3%	2.6%	2.6%	3.1%	1.2%	4.0%	2.0%	4.0%	1.3%	2.2%	3.2%	2.9%	0.0%	2.5%	3.2%	2.2%	2.3%	2.8%	2.9%	
C QUALITY																						
c01: coordination: coordination of health information an	6.6%	8.7%	5.9%	5.1%	6.7%	7.5%	4.3%	10.3%	5.0%	6.8%	6.4%	7.8%	4.6%	7.3%	0.0%	3.8%	2.1%	12.9%	4.7%	2.8%	13.4%	
c02: information transfer: flow of information, exchange	5.2%	3.6%	5.7%	5.1%	5.2%	5.6%	4.3%	6.3%	4.7%	4.7%	5.7%	5.6%	4.6%	5.5%	1.6%	3.8%	4.8%	7.5%	3.1%	5.0%	6.7%	
c03: access: keeping health information for patients acce	5.9%	8.0%	5.3%	7.7%	5.8%	6.5%	4.3%	7.4%	5.2%	6.1%	5.7%	5.0%	7.3%	6.3%	3.3%	7.0%	4.8%	5.4%	7.8%	5.6%	4.4%	
c04: transparency (as standard or requirement, quality in	7.6%	13.0%	5.9%	2.6%	8.0%	9.2%	3.7%	8.0%	7.5%	8.3%	7.0%	8.1%	6.9%	7.7%	6.6%	6.3%	5.3%	8.6%	6.3%	6.7%	10.5%	
c05: ownership of notes (health information): sign of and	3.1%	3.6%	3.0%	2.6%	3.2%	3.4%	2.5%	1.1%	4.0%	3.6%	2.7%	4.5%	0.9%	3.1%	3.3%	1.9%	2.7%	4.8%	1.6%	1.1%	6.4%	
c06: patient protection: safety, confidentiality and privac	4.2%	15.9%	2.1%	10.3%	5.0%	5.3%	5.6%	4.6%	5.7%	5.8%	5.0%	6.4%	3.7%	5.3%	6.6%	5.1%	5.3%	4.3%	6.3%	3.3%	7.0%	
c07: record: keeping track of health information (chronic	12.2%	5.8%	14.2%	5.1%	12.7%	12.8%	10.5%	9.1%	13.5%	15.5%	9.1%	12.3%	11.9%	12.0%	14.8%	12.7%	11.2%	14.5%	10.2%	12.8%	11.0%	
c08: staying up-to-date (‘tuned’) with care, health inform	6.3%	2.2%	7.5%	5.1%	6.3%	6.5%	5.6%	6.3%	6.2%	8.3%	4.4%	6.4%	6.0%	5.7%	9.8%	6.3%	7.5%	5.4%	4.7%	6.1%	5.2%	
c09: clarity of information: general sign and facilitator of	4.3%	4.3%	4.3%	2.6%	4.5%	5.1%	2.5%	6.9%	3.2%	4.7%	4.0%	3.9%	5.0%	4.0%	9.0%	3.2%	4.8%	5.4%	6.3%	3.3%	5.2%	
c10: clarity of health information: adherence and compli	10.9%	7.2%	12.1%	7.7%	11.2%	11.1%	10.5%	12.0%	10.5%	11.9%	10.1%	10.6%	11.5%	10.4%	16.4%	8.2%	12.8%	12.9%	7.8%	11.1%	12.2%	
c11: clarity of information: concerns over lack of it (e.g., t	2.8%	5.1%	2.1%	0.0%	2.0%	2.9%	2.5%	2.3%	3.0%	5.2%	2.7%	3.9%	0.9%	2.9%	1.6%	3.8%	1.1%	3.2%	4.7%	1.7%	4.1%	
c12: concerns about fragmentation, incompleteness or p	1.4%	1.4%	1.4%	2.6%	1.3%	1.7%	0.6%	1.1%	1.5%	1.1%	1.7%	2.2%	0.0%	1.6%	0.0%	1.9%	0.5%	1.6%	2.3%	0.6%	2.3%	
c13: concerns about candor, veracity/truthfulness, accur	2.3%	8.0%	0.5%	5.1%	2.0%	2.7%	1.2%	0.6%	3.0%	2.5%	2.0%	2.8%	1.4%	2.6%	0.0%	2.5%	2.1%	1.1%	3.1%	1.7%	3.5%	
c14: quality of documentation: error avoidance (procedu	7.5%	4.3%	8.4%	2.6%	7.8%	7.2%	8.0%	9.7%	6.5%	5.0%	9.7%	8.4%	6.0%	7.7%	4.9%	7.6%	7.5%	7.5%	7.8%	8.3%	7.6%	
c15: efficiency: using time and other resources more effi	2.8%	2.2%	3.0%	0.0%	3.0%	3.6%	0.6%	4.6%	2.0%	3.6%	2.0%	2.8%	2.8%	3.1%	0.0%	1.9%	3.2%	3.8%	1.6%	2.2%	5.8%	
D SELF-CARE																						
d01: generally facilitating self-engagement and involvem	7.8%	6.5%	8.2%	0.0%	8.4%	8.2%	6.8%	8.0%	7.7%	8.3%	7.4%	8.1%	7.3%	8.1%	6.6%	5.7%	11.2%	7.0%	6.3%	5.6%	12.2%	
d02: reinforcing self-care and self-management skills, abi	7.8%	7.2%	8.0%	10.3%	7.6%	8.2%	6.8%	12.6%	5.7%	8.6%	7.0%	9.0%	6.0%	7.9%	8.2%	5.7%	10.7%	7.0%	9.4%	5.6%	9.9%	
d03: motivation (e.g., for making and/or keeping healthy	4.9%	1.4%	5.9%	0.0%	5.2%	5.1%	4.3%	5.1%	4.7%	5.0%	4.7%	5.6%	3.7%	4.3%	9.8%	3.2%	7.0%	4.8%	5.5%	5.0%	5.8%	
d04: patient-centeredness (sign of; tool for); patient has	10.2%	8.7%	10.7%	10.3%	10.2%	11.1%	8.0%	11.4%	9.7%	11.9%	8.7%	10.9%	9.2%	10.6%	8.2%	10.8%	10.2%	11.1%	10.2%	14.1%	7.2%	13.4%
d05: control: patient feels more in control; reduced help	9.7%	10.9%	9.4%	5.1%	10.1%	10.6%	7.4%	12.0%	8.7%	12.2%	7.4%	9.5%	10.1%	10.0%	4.9%	6.3%	10.2%	12.4%	7.8%	6.7%	15.7%	
d06: active encouragement (e.g., to continue taking care	9.0%	5.1%	10.3%	7.7%	9.1%	9.2%	8.6%	9.1%	9.0%	12.6%	5.7%	9.2%	8.7%	8.3%	16.4%	8.9%	11.2%	8.1%	10.2%	5.6%	10.5%	
d07: notes serve to monitor health and self-care options	3.0%	1.4%	3.4%	0.0%	3.2%	3.1%	2.5%	2.3%	3.2%	2.9%	3.0%	3.1%	2.8%	2.9%	3.3%	2.5%	3.2%	3.8%	0.8%	2.2%	2.9%	
d08: patients less challenged, distracted during visit: can	3.6%	4.3%	3.4%	2.6%	3.7%	4.6%	1.2%	6.3%	2.5%	4.7%	2.7%	2.5%	5.5%	3.7%	1.6%	5.7%	2.1%	3.8%	4.7%	2.8%	3.5%	
E FUTURE REFINEMENT (IMPROVEMENTS)																						
e																						

**Appendix 5 [Table]:
Results QIA: Identified Themes and Referring Quotes**

Aspect / Theme (Sample)	Related / Referring Patient Quote (Sample)
<p>Member checking → FTA codebook (themes) confirmed; e.g.:</p> <ul style="list-style-type: none"> - Improved <u>understanding</u> <ul style="list-style-type: none"> o Understanding one's own health o Confirming understanding o Refreshing memory - Better <u>relationship</u> <ul style="list-style-type: none"> o Higher trust o Better communication o Higher confidence (comfort, ease) - Better <u>quality</u> <ul style="list-style-type: none"> o Transparency as indicator of quality o Keeping track of information o Adherence/compliance (clarity) o Health benefits/harm avoidance o Efficiency - Strengthened <u>self-care</u> <ul style="list-style-type: none"> o Engagement o Activation (proactive role) o Involvement o Patient-centeredness o Feeling in control (less helpless) 	<p><i>"It improved my understanding" (Daniel, 77)</i> <i>"It improves my understanding of my own health" (William, 66)</i> <i>"What was important to me was the confirmation of what went on at the visit" (J. Marie, 82)</i> <i>"I look at Open Notes as a reassuring memory aid" (William, 66)</i></p> <p><i>"By having Open Notes, I feel that we have a better relationship because some of the clouds are gone. We're not talking through a fog" (David, 75)</i> <i>"It brings the doctor and the patient closer together" (Elaine, 66)</i> <i>"Trust is a big thing. And it does relate to Open Notes, I feel. [...] Because I can read her notes [...], I trust her more" (Cheryl, 58)</i> <i>"I think it's important to know that I'm trusted as part of this relationship. And it helps me trust the doctor as well" (Beverly, 67)</i> <i>"With Open Notes being there, communication got better" (Hanna, 87)</i> <i>"I feel that she really cares about me. I read the notes and I get reassured" (Elaine, 66)</i> <i>"[Open Notes] makes me feel more confident" (J. Marie, 82)</i></p> <p><i>"Transparency [...] is a quality indicator" (Hanna, 87)</i> <i>"It's a continuing reference. It's an archive. [...] I can always refer back to it if need be" (David, 75)</i> <i>"[Reading the notes] clears things up for me" (Cheryl, 58)</i> <i>"I can better conform to what she is recommending me to do" (Mary B., 60)</i> <i>"I was [online] and happened to see that I was taking the wrong amount of prescription" (Cheryl, 58)</i> <i>"I think it makes the whole interaction [...] more effective. More efficient" (David, 75)</i></p> <p><i>"Having the [...] records online [...] helped me definitely be more engaged. [Open Notes] supplemented that" (Beverly, 67)</i> <i>"[It] engages me" (William, 66)</i> <i>"I take an active role [...]. That's a tool to make that happen" (Mary B., 60)</i> <i>"You're more involved in your medical care – by having that note. [...] Doctors are more involved, and patient is" (Linda, 69)</i> <i>"I want to know what's happening. I want to be right at the forefront" (Ellen G., 73)</i> <i>"I feel I'm more apt to talk to her about different things" (Cheryl, 58)</i></p>
Few safety/privacy concerns	<i>"I don't see any safety concerns" (Cheryl, 58)</i>
Limited sharing of notes	<i>"I just don't want anyone to share it. [...] That's my own personal thing" (Ellen G., 73)</i>
Withholding of information	<i>"I think it takes away from the visit when you can't be honest. [...] I definitely would not want it read by anybody else" (J. Marie, 82)</i>
<p>More interactivity (in the future)</p> <ul style="list-style-type: none"> - Want to respond/comment on notes - Want to have errors corrected - Little desire to co-generate notes 	<p><i>"Would be good if at the end of the notes: 'Is there something here that you see as not correct or something?'" (Ellen, 66)</i> <i>"The patient should have an opportunity to comment, and the doctor give feedback" (Mary B., 60)</i> <i>"There should be a few check boxes where you could say, understood, will do, confused, or something" (David, 75)</i> <i>"I think there needs to be a mechanism for requesting corrections" (Beverly, 67)</i> <i>"I think that the doctor's note should be the doctor's note" (Mary B., 60)</i></p>
<p>Putting some notes under an 'embargo'</p> <ul style="list-style-type: none"> - Caution against 'automated openness' - Like to have personal conversation, individual face-to-face time with doctors (direct communication) 	<p><i>"That is the question of embargo. [...] I would not want to read that I have cancer, nakedly on the screen. [...] I want this to be told to me in person by a medical professional whom I trust. [...] Conditions with fatal outcomes, I think, need to be mediated by a human being!" (Hanna, 87)</i> <i>"I guess my concern would be reading something at a time where you are physically not prepared to deal with what actually happened" (Mary B., 60)</i> <i>"Openness [...] needs to be done with sensitivity to the emotional impact of different kinds of news. [...] There is no reason to hide that from me. But I don't want to see it [in the record/notes] before a conversation" (William, 66)</i></p>
⇒ Characteristic (indicative) 'summarizing' statements	<p><i>"Expand it; include specialists, and almost everybody who is involved in [my] care. And expand the system and make it more inclusive" (Elaine, 66)</i> <i>"I do think that transparency is key and is quality of care. I think it's important for patients to understand truthfully what their situation is and how they can help themselves and be educated enough to be able to ask the right questions to physicians. Every patient has that right. [...] And I think that Open Notes helps that" (Mary B., 60)</i></p>