

Figure 1. Study flowchart

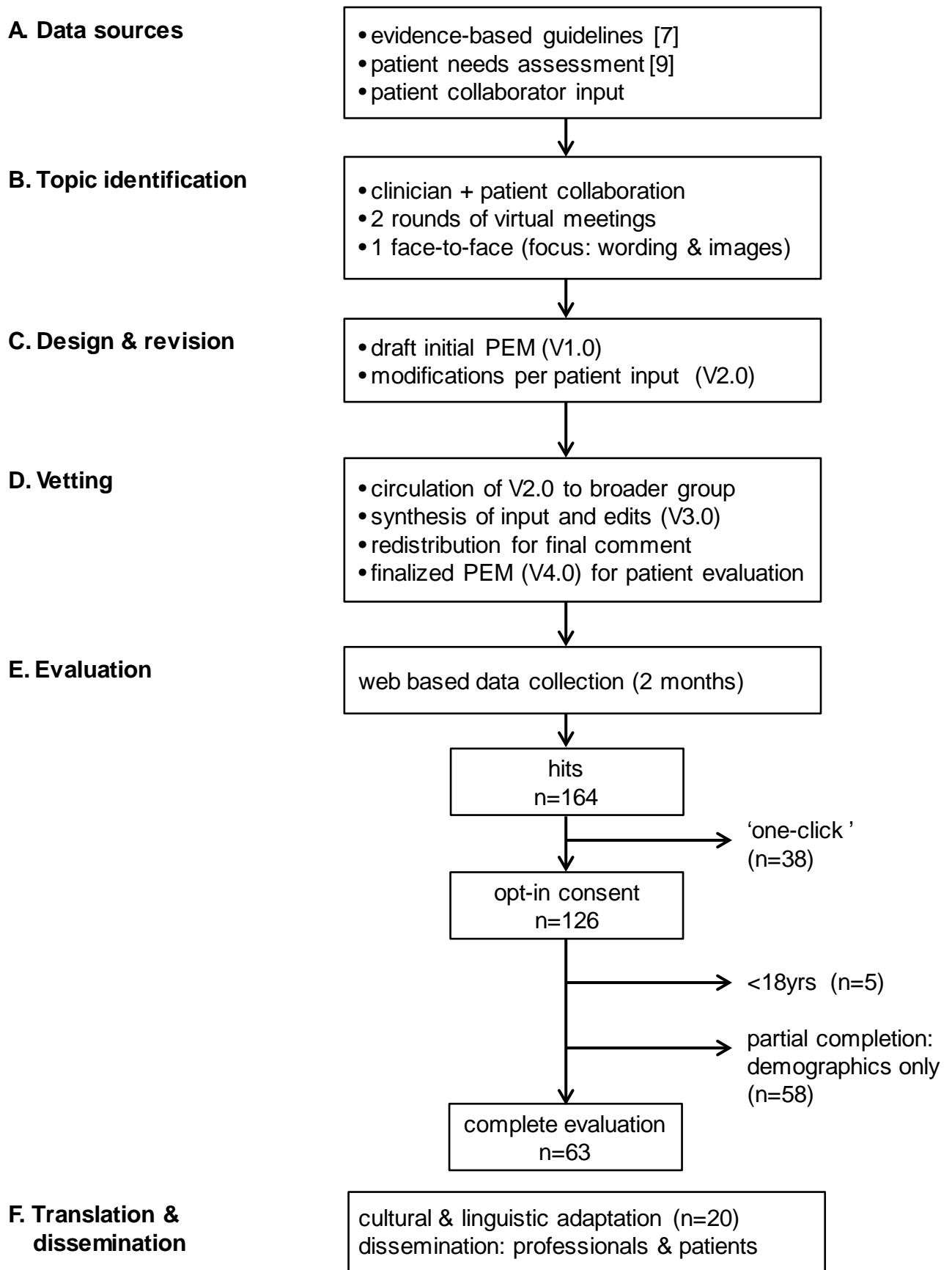


Table 1. Summary of readability of co-created patient education material

Summary statistics (5 pages, 203 sentences + images)		
word count = 1,654		
character count = 8,251		
complex words (≥ 3 syllables) = 268		
average characters per word = 5		
average words per sentence = 8.1		
Instrument	Score	Grade level
Flesch Reading Ease	67.6	8-9 th
Flesch-Kincaid Reading Level	5.9	6 th
Gunning Fog Index	9.7	9-10 th
Coleman Liau Index	8.8	8-9 th
SMOG	9.7	9 th
Automated Readability Index	6.1	6 th
Mean	8.0	8th grade

Table 2. Patient Characteristics (n=63)

Sex	n (%)
male	42 (67%)
female	21 (33%)
Age	
18-29	13 (21%)
30-39	24 (38%)
40-49	17 (27%)
50-59	5 (8%)
60+	4 (6%)
Children	
none	42 (66%)
biologic children	14 (22%)
adopted children	7 (11%)
Education level	
high school/vocational	17 (27%)
university	25 (40%)
post-Graduate	21 (33%)
Health literacy*	
adequate	52 (83%)
inadequate	11 (17%)
Health experiences	
seen at academic center	39 (62%)
had genetic testing	36 (57%)
received genetic counseling	12 (19%)

* health literacy as assessed by (13,14)

Table 3. PEMAT Understandability and actionability of co-created materials (n=63)

PEMAT topic/category	% agree
Content	
The material makes its purpose completely evident.	92.1%
The material does not include information or content that distracts from its purpose.	90.5%
Word choice & style	
The material uses common, everyday language.	93.7%
Medical terms are used only to familiarize the audience with the terms. When used, medical terms are defined.	93.7%
The material uses the active voice (e.g. action verbs).	95.2%
Use of numbers	
Numbers appearing in the material are clear and easy to understand.	96.8%
The material does not expect the user to perform calculations.	96.8%
Organization	
The material breaks or "chunks" information into short sections.	93.7%
The material's sections have informative headers.	95.2%
The material presents information in a logical sequence.	93.7%
The material provides a summary.	96.8%
Layout & design	
The material uses visual cues to draw attention to key points.	95.2%
Visual aids	
The material uses visual aids whenever they could make content more easily understood.	95.2%
The material's visual aids reinforce rather than distract from the content.	92.1%
The material's visual aids have clear titles or captions.	95.2%
The material uses illustrations and photographs that are clear and uncluttered.	88.9%
The material uses simple tables with short and clear row and column headings.	97.5%
Total understandability	94.2%
Actionability	
The material clearly identifies at least one action the user can take.	95.2%
The material addresses the user directly when describing actions.	92.1%
The material breaks down any action into manageable, explicit steps.	92.5%
The material provides a tangible tool (e.g. checklists) whenever it could help the user take action.	94.5%
The material explains how to use the charts, graphs, tables, or diagrams to take actions	70.7%
The material uses visual aids whenever they could make it easier to act on the instructions.	92.0%
Total actionability	90.5%

Table 4. Patient comments (n=52) regarding the co-created materials

Category	Representative quote(s)
thanks / approval n=19	<ul style="list-style-type: none"> • “I was very impressed and I think my friends and family will find it easy to understand” • “I am glad that there is a clear male/female explanation. Often materials I find focus predominantly on the males”
content n=11	<ul style="list-style-type: none"> • “Elaborate on infertility and treatment” • “I think you may be under discussing the life-long emotional and psychological impact”
formatting n=10	<ul style="list-style-type: none"> • “It felt like the pages were a bit full but I can appreciate it must have been hard to provide all the information necessary in only 5 pages” • “I think if there was a way to click on each section for more detailed info that might help”
personal concerns n=9	<ul style="list-style-type: none"> • “Other rare conditions that can also be evident in patients with KS/CHH... ..Explain that patients can have additional illnesses besides KS/CHH” • “It might be helpful to state that anosmia is permanent. Of course it is most important to focus on the hormonal component, but there are definitely considerations in dealing with anosmia as well”
dissemination n=3	<ul style="list-style-type: none"> • “It would be great if you could translate into several languages to reach more people”