Appendix I: Definition of Participatory Health and Questions used in the First Round of the Survey

Participatory Health through Social Media is an active digital collaboration between service users, patients, general public, and healthcare professionals aiming to enhance health, through any form of social medial including but not limited to: Social Networks (e.g., Facebook); Professional Networks (e.g., LinkedIn); Thematic Networks (e.g., PatientsLikeMe, TuDiabetes); Microblogs; Blogs; Wikis; Forums/Listservs; Social Photo and Video Sharing Tools; Collaborative Filtering Tools (e.g., RSS, recommender systems, tagging); Multi-User Virtual Environments (e.g., Second Life); Social applications and games; Integration of Social Media with Health Information Technologies (e.g. EHRs, PACS, SNOMED) and others.

Questions:

i. What ethical aspects/issues should be considered in Participatory Health through Social Media from the patients, service users, and general public’s perspective?

ii. What ethical aspects/issues should be considered in Participatory Health through Social Media from the healthcare professionals’ perspective (including clinical and allied health professions)?

iii. What ethical aspects/issues should be considered in Participatory Health through Social Media from the Health IT professionals’ perspective (health informaticians, etc.)?

iv. What ethical aspects/issues should be considered in Participatory Health through Social Media from the policy makers’ perspective?

Appendix II: Summary of First Round Survey Results

Table 1 Respondents' self-reported profession and country of residence

Characteristics	First round Number (%) (n=26)
Profession	
Researcher	7 (26.9%)
Professor	5 (19.2%)
Computer Engineering or Informatician	3 (11.5%)
Clinical or Biomedical Informatician	2 (7.7%)
Healthcare Consultant or Health Information Specialist	2 (7.7%)
Medical Doctor	2 (7.7%)
Attorney	1 (3.8%)
Managing Director or CEO	1 (3.8%)
PhD Candidate	1 (3.8%)
Psychiatrist	1 (3.8%)
Psychologist	1 (3.8%)
Country of residence	
USA	9 (34.6%)
Spain	6 (23.1%)
Switzerland	5 (19.2%)
Norway	3 (11.5%)
Austria	1 (3.8%)
Finland	1 (3.8%)
Qatar	1 (3.8%)

Table 2 List of themes identified per each perspective

Patients/service users/general public’s perspective	
Themes	**Comments**
Data privacy	Anonymisation of data / Avoid Re-identification through data linking / Clarification of data reuse
Data security	
Education for patients	Risks of sharing data / Informed consent
Intellectual property	Commercialization / No compensation theory
Quality assurance	Reliability of provided information
Healthcare professionals’ perspective	
Themes	**Comments**
Data privacy	Patient confidentiality / Participating in patient-focused groups / Clarification of data reuse
Data security	
Education of health professionals	Awareness of risks, do's and don'ts (e.g., sharing patient data) / Lack of clarity on how to integrate information from these channels into patient care / Potential for blurring professional boundaries with access to social media information of patients and/or colleagues
Intellectual property	Commercialization / No compensation theory
Quality assurance	Evidence-based information and interventions with links to underlying evidence / Evidence for risk and benefits
Responsible use	Suitability of provided information / Difficulties to generalize recommendations due to varying characteristics of persons / Cultural differences
Work overload for health professionals	Excess information burden / Screen time for providers
IT professional perspective	
Themes	**Comments**
Data privacy	Transparency related to what data are collected and how they will be used
Data security	

Education for IT professionals	Potential lack of consideration of cultural background/language in user interface design
Responsible use	Potential lack of consideration of cultural background in language processing
Policy makers' perspective	
Themes	**Comments**
Balance between innovation and law/regulatory requirements	
Data privacy	
Data security	
Education for policy makers	
Intellectual property	Commercialization / No compensation theory
Quality assurance	Evidence-based information and interventions with links to underlying evidence / Evidence for risk and benefits / Data Accuracy / Stakeholders needs fulfilment
Responsible use	Aspects as gender, nationality, vulnerable populations … are ethically handled / Universal access

Appendix III: Examples of Thematic Analysis of First Round Survey Results

Regarding the policy makers' perspective, the responses were inductively coded to generate 19 different codes which were thematically organized into four major themes: patients, information, participation, and governance. (See Appendix III, Table 3).

From the perspective of a policy maker regarding the issue of participatory health for patients a number of important points were made by respondents. For example, relating to vulnerable populations, one respondent noted that policy makers should be cognizant about the effects of participatory health technologies on vulnerable populations:

> *Often, the point of view of vulnerable people such as minor patients who are female and of color, new immigrants, those with low literacy, those who cannot know the real uses of the data being collected, is not taken into account.*

There is a need for policy makers to become more aware of how participatory health is being used by patients, as one respondent noted: *Educate [policy makers] about what do patients do, and what are the implications [of using] different [participatory health] services.* Furthermore, policy makers should be aware of the digital divide between patients, as one respondent noted: *[Policy makers need to know about the] digital divide in the population, [especially] between those who understand and use eHealth/mHealth and those who don't.*

Therefore, policy makers should study the risks and benefits of participatory health from a patient's perspective and ensure that the "*benefits for patients must substantially outweigh [the] risks]*", as noted by one respondent.

With regards to the second theme of information, policy makers need to ensure that patient data should be accurate and transparent and should be protected from misuse through commercialization or the ability to re-identify patients. As one respondent noted:

> *Unawareness of the social media users of the risk of exposing their personal health data or personal situation [is more prominent] as re-identification becomes more powerful,*

For participation, policy makers need to understand the different information needs of stakeholder organizations or individuals, and with patients, policy makers need to ensure that patients have the same rights to access social media platforms to ensure equal participation. Policy makers should have the right to opt-out of any technological platform the organization may commit too, according to a respondent, and therefore, policy makers should be selective on the participatory platforms used with patients.

With regards to governance, it is important that the policy makers act ethically and responsibly with regards to participatory health platforms, as one respondent noted:

> *Policy makers need to be mindful of the threats and benefits to society as a whole--a society places great trust in its medical professionals and expects them to uphold the highest ethical standards. Policy makers must take care not to incur the impression (or reality) of undue influence from those who may have lower ethical standards. Many respondents discussed the role of policy makers in the development of responsible and innovative participatory health platforms.*

There were a few different comments with regards to the role in applying responsible innovation to participatory health platforms. One respondent noted:

> *Regulation suppresses innovation. But, innovation is frequently ethically corrupted and self-interested -- especially in the novel world of consumer tech. The two are difficult to reconcile. Too little public health attention is paid to the possible risks of technology use. Supporting unproven remedies is like waging "war on cancer" with quackery. The money has a way of controlling policy beyond the power of good faith and public interest. There is a "technology-industrial complex" that is wealthy and can disguise both incompetence and malevolence behind slick PowerPoints.*

In summary, there are many issues from the perspective of a policy maker that need to be considered when trying to plan, implement, and evaluate participatory-related health technologies. We used this information in the development of the second round of questions for the survey.

Table 3 Themes related to the analysis of policy makers' perspective from round 1.

Themes	Codes
Patients	• Vulnerable populations • Patient benefits and risks • Educate patients • Patient participation • Digital divide
Information	• Data re-identification • Commercializing data • Information transparency • Data accuracy
Participation	• Policy makers insights and interactions • Equal participation • Understanding stakeholder needs • Opting out of initiatives • Participation limitation • Service access
Governance	• Law and regulation • Ethically responsible policy makers • Ethical guidelines • Responsible innovation

Appendix IV: Summary of Second Round Survey Results

Table 4 Respondents' self-reported profession and country of residence

Characteristics	**Second round** **Number (%)** **n = 33**
Profession	
Nurse	7 (21.2%)
Professor	7 (21.2%)
Researcher	7 (21.2%)
Medical doctor	4 (12.1%)
Physiotherapist	3 (9.1%)
Clinical or biomedical informatics	2 (6.1%)
Managing director or CEO	2 (6.1%)
Product manager	1 (3.0%)
Country of residence	
Spain	8 (24.2%)
USA	8 (24.2%)
Greece	4 (12.1%)
Qatar	4 (12.1%)
Switzerland	2 (6.1%)
Australia	1 (3.0%)
Austria	1 (3.0%)
Cyprus	1 (3.0%)
Israel	1 (3.0%)
Norway	1 (3.0%)
Romania	1 (3.0%)
UK	1 (3.0%)

Table 5 Perceived importance of ethical issues for different stakeholders (patients/general public; healthcare professionals; IT professionals; policy makers)

Importance	**Absolutely essential**	**Very important**	**Moderately important**	**Slightly important**	**Not at all important**
Patients/general public's perspective (n=33)					
Quality assurance	18 (54.5%)	14 (42.4%)	1 (3.0%)	0 (0%)	0 (0%)
Data privacy	20 (60.6%)	12 (36.4%)	1 (3.0%)	0 (0%)	0 (0%)
Data security	18 (54.5%)	11 (33.3%)	3 (9.1%)	1 (3.0%)	0 (0%)
Ownership of data	11 (33.3%)	15 (45.5%)	5 (15.2%)	2 (6.1%)	0 (0%)
Education for patients	14 (42.4%)	14 (42.4%)	5 (15.2%)	0 (0%)	0 (0%)
Healthcare professionals' perspective (n=33)					
Quality assurance	22 (66.7%)	11 (33.3%)	0 (0%)	0 (0%)	0 (0%)
Data privacy	21 (63.6%)	10 (30.3%)	1 (3.0%)	1 (3.0%)	0 (0%)
Data security	19 (57.6%)	10 (30.3%)	1 (3.0%)	2 (6.1%)	0 (0%)
Ownership of data	12 (36.4%)	11 (33.3%)	4 (12.1%)	4 (12.1%)	1 (3.0%)
Education of health professionals	15 (45.5%)	16 (48.5%)	1 (3.0%)	0 (0%)	0 (0%)
Responsible use	14 (42.4%)	14 (42.4%)	4 (12.1%)	0 (0%)	0 (0%)
Work overload for health professionals	5 (15.2%)	19 (57.6%)	7 (21.2%)	1 (3.0%)	0 (0%)
IT professionals' perspective (n=33)					
Data privacy	22 (66.7%)	9 (27.3%)	1 (3.0%)	0 (0%)	0 (0%)
Data security	24 (72.7%)	7 (21.2%)	0 (0%)	0 (0%)	0 (0%)
Education for IT professionals	9 (27.3%)	16 (48.5%)	7 (21.2%)	0 (0%)	0 (0%)

Responsible use	10 (30.3%)	16 (48.5%)	6 (18.2%)	0 (0%)	0 (0%)
Policy makers' perspective (n=33)					
Quality assurance	14 (42.4%)	13 (39.4%)	4 (12.1%)	1 (3.0%)	0 (0%)
Data privacy	21 (63.6%)	9 (27.3%)	2 (6.1%)	0 (0%)	0 (0%)
Data security	21 (63.6%)	6 (18.2%)	4 (12.1%)	1 (3.0%)	0 (0%)
Ownership of data	16 (48.5%)	13 (39.4%)	3 (9.1%)	0 (0%)	0 (0%)
Education for policy makers	12 (36.4%)	17 (51.5%)	3 (9.1%)	0 (0%)	0 (0%)
Responsible use	12 (36.4%)	19 (57.6%)	1 (3.0%)	0 (0%)	0 (0%)
Balance between innovation and law	16 (48.5%)	12 (36.4%)	3 (9.1%)	1 (3.0%)	0 (0%)

Table 6 Prioritized ethical issues importance for different stakeholders (patients/general public; healthcare professionals; IT professionals; policy makers)

	Overall							
	Strength Score	Mean	Endorsed	Overall Rank	IT Professionals' Rank	Health Professionals' Rank	Policy Makers' Rank	Others' Rank
Patients/general public's perspective								
Data privacy	151	4.58	60.61	1	1	1	1	1
Quality assurance	149	4.52	54.55	2	2	3	4	5
Data security	145	4.39	54.55	3	3	2	2	4
Education for patients	141	4.27	42.42	4	4	4	3	2
Ownership of data	134	4.06	33.33	5	5	5	5	3
	Strength Score	Mean	Endorsed	Rank	IT Professionals' Rank	Health Professionals' Rank	Policy Makers' Rank	Others' Rank
Healthcare professionals' perspective								
Quality assurance	154	4.67	66.67	1	1	1	1	1

Data privacy	**150**	**4.55**	**63.64**	**2**	**2**	**1**	**1**	**2**
Data security	**142**	**4.44**	**59.38**	**3**	**3**	**3**	**5**	**5**
Education of health professionals	**142**	**4.44**	**46.88**	**4**	**4**	**4**	**5**	**3**
Responsible use	**138**	**4.31**	**43.75**	**5**	**5**	**6**	**3**	**3**
Ownership of data	**125**	**3.91**	**37.50**	**6**	**7**	**5**	**3**	**6**
Work overload for health professionals	**124**	**3.88**	**15.63**	**7**	**6**	**7**	**6**	**7**
	Strength Score	**Mean**	**Endorsed**	**Rank**	**IT Professionals' Rank**	**Health Professionals' Rank**	**Policy Makers' Rank**	**Others' Rank**
IT professionals' perspective								
Data privacy	**149**	**4.66**	**68.75**	**1**	**1**	**2**	**2**	**2**
Data security	**148**	**4.77**	**77.42**	**2**	**1**	**1**	**1**	**1**
Responsible use	**132**	**4.13**	**31.25**	**3**	**4**	**3**	**2**	**3**
Education for IT professionals	**130**	**4.06**	**28.13**	**4**	**3**	**4**	**2**	**4**
	Strength Score	**Mean**	**Endorsed**	**Rank**	**IT Professionals' Rank**	**Health Professionals' Rank**	**Policy Makers' Rank**	**Others' Rank**

Policy makers' perspective									
Data privacy	**147**	**4.59**	**65.63**	**1**	**1**	**2**	**3**	**1**
Data security	**143**	**4.47**	**65.63**	**2**	**2**	**1**	**3**	**3**
Ownership of data	**141**	**4.41**	**50.00**	**3**	**6**	**6**	**7**	**2**
Balance between innovation and law	**139**	**4.34**	**50.00**	**4**	**3**	**5**	**3**	**5**
Responsible use	**139**	**4.34**	**37.50**	**5**	**7**	**7**	**3**	**4**
Education for policy makers	**137**	**4.28**	**37.50**	**6**	**5**	**4**	**1**	**7**
Quality assurance	**136**	**4.25**	**43.75**	**7**	**4**	**3**	**1**	**6**

Strength Score: Total points per ethical issue as a sum of total points resulting by multiplying the number of participants with the value that they selected in the Likert scale.

Mean: Mean rating of the items from the Likert scale labeled Absolutely essential = 5, Very important = 4, Moderately important = 3, Slightly important = 2, Not at all important = 3.

Endorsed: The percentage of panelists who selected the highest rating "Absolutely essential"

Rank: The rank assigned to ethical issues based first on Strength Score and then on the "Endorsed" score where Strength Scores were the same.