Annex 1 - Shared motivations, goals and values in the practice of personal science - A community perspective on self-tracking for empirical knowledge

Semi-structured interview script and prompts

1) Introduction
   a) Quick personal intro from interviewers.
   b) Basic details about our study on personal science (why it is important and what we are exploring).
   c) Reminder of consent for interview, and the possibility to withdraw from the study at any time.
   d) Additional information about the interviewer(s), role and background.
   e) Quick overview of the four areas of questions for the interview, and its semi-structured approach.

2) Background questions
   a) Tell me a little bit about your background...
      ■ Profession
      ■ Studies
      ■ Place of residence
   b) Tell me more about your experience / project regarding self-research...
      ■ Research question / topic
      ■ Time dedication
      ■ Main finding(s) or outcomes so far
Previous experience with self-research / self-tracking

3) Motivation, goals and values questions
   a) Why did you decide to start to do self-tracking?
      - What initially moved you to initiate the research
   b) What do you think are your main reasons for participating in the Open Humans initiative?
      - Research topic
      - Learning new information
      - Contributing to empirical knowledge
      - Enjoying research tasks
      - Sharing goals and values
      - Helping others
      - Improving health and lifestyle
   c) (If ongoing project) Tell me more about what moves you to regularly self-track for your research.
      - Regarding your own questions
      - Regarding other self-trackers
      - Regarding the knowledge you are generating
   d) (If stopped self-tracking) Why did you stop participating in your self-research / Open Humans?
      - Main barriers or complications during the process (Lack of time? Knowledge? Protocol? Support?)

4) Learning-related questions
   a) Now please tell me more about the main things you have learned through your self-research process...
      - Scientific literacy
      - Content-specific knowledge
      - Changes in behaviour
      - Other offtopic knowledge and skills
      - Research protocols/mechanics
b) **How did you learn that?**
- Interactions via Open Humans
- External resources
- Project documentation (“internal” resources)
- Accidentally
- Following a plan/contributing to a research task or problem
- Sharing personal advances

c) **What are the things you would like to learn or discover in the future regarding self-research?**
- How Open Humans can provide support (or not)
- How this can be relevant to yourself and others

5) **Community & platform questions**
   a) **Tell me about your experience with the Open Humans / self-research / self-tracking community...**
   - Online meetings and discussions
   - Relationships between self-researchers / facilitators
   - Regarding other self-trackers projects

   b) **Tell me more about how you contribute or interact with other self-trackers...**
   - Regarding peer support
   - Regarding tech
   - Sharing your research process and questions

   c) **What’s your experience using the Open Humans platform?**
   - How it works for you
   - Regarding sharing self-tracking data (or not)
   - What would you improve or change

6) **Final comments**
   a) **What’s your experience with citizen science? Do you think it is related to personal science?**
   b) More information on the study progress and steps
   c) Provide interviewer contact information, and ask permission for further contact (second shorter interview, only if needed for specific questions)
Codebook for interviews (v4)

This version of the codebook covers 5 main motivation, goals and values related categories for the classification of excerpts from 22 semi-structured interviews (to members of the Open Humans community and to other individuals doing self-tracking for self-research). The codebook has been based mainly on previous conceptual frameworks combining previous approaches for the study of motivations in citizen science (Jennett et al., 2016), the inquiry cycle of personal science (Wolf and De Groot, 2020) and collaboration in peer-production (Spaeth and Niederhöfer, 2020), as well as concepts related to scientific values like the Mertonian norms (Merton, 1973). It also reflects for each category the different sub-codes applied for the interpretation and analysis of these categorised fragments, in connection to other studies and literature and their respective frameworks or units of analysis (mainly on personal science, self-tracking, personal informatics and/or citizen science).

| Category | Examples | Criteria | Specific sub-codes |
|----------|----------|----------|--------------------|
| **1.1** Improving personal conditions: References to personal health situations, symptoms or problems requiring attention, as well as motivations related to well-being and / or day-to-day mood, quality of life, etc. | “Yeah, so basically I have diabetes and just by nature of trying to get control of the disease, I have to do a lot of self-experimentation to figure out, you know, medication doses, influence of different foods, exercise, etc” // “But for me, I know it's a journey. It's a never-ending journey of getting to know yourself and I mentioned the weight thing because it's so prevalent in the sense like it shows, it feels different, and it's also complex” | As a potential key, transversal motivation for many self-researchers, it is important as an inclusion criteria to add this code when there's an explicit reference to a personal health condition and/or general well-being. It includes ambiguous mentions of possible conditions inherited or known in the participant's family members, as well as references about knowing oneself better, when in relation to life-style. | Motivated by which health conditions or personal life-style? |
| A. Improve specific health condition / treatment | | | |
| B. Improve lifestyle / general well being | Related approaches: Gimpel, Nißen and Görlitz, 2013; Choe, Lee and Schraefel, 2015; Lupton and Smith, 2018; Ajana, 2020. | |
| **1.2** Enjoying data, tech or research activity: Signs of involvement and engagement connected to intense | “So beyond work, it's something I really value, I like to spend a lot of time on it [gathering data].” // “And so the motivation was I have to now get into hardware because I need to get | This code has evolved to include mentions related to “non-patient” and no academic or professional | Moved by enjoyment, curiosity or interest in what type of specific activity? |
| 1.3 | **Extrinsic motivations**: The expression of motivation is in a great way determined by the connection with the professional or scientific career of the participant. Also engaging with self-research as an opportunity to develop or contribute to new products for the market. |
| --- | --- |
| **1.3** | “I'm not putting all my data out there for anybody because I think we [research group] need to be the first ones to understand what's in the data and also publish my own papers about my data” // "I'm also looking if there's any business opportunity, like if you could just start a company that if suddenly there was a huge demand like all doctors they want to to have a nice dashboard where they can look at their patients data, that would be an amazing opportunity to build such a service, but I know right now it's not the case, doctors are not asking for this kind of thing, unfortunately” The only “extrinsic” motivations in this case (also as possible self-mention to scientific contributions), refers to being interested also for “meta” research purposes. Similarly to the rest of categories, it can be identified among other intrinsic motivations in the same participant stories, even the same sentences. |
| **Motivated by what type of extrinsic factors?** | A. Acquiring skills / experience for professional career  
B. Demonstrating work / results in a specific area  
C. Involvement in a business / product opportunity  
Related approaches: Lee, 2014; Jin et al., 2020; West and Pateman, 2016. |

| 1.4 | **Contributing to empirical knowledge**: Mentions to specific research topics, results, questions, issues, protocols or advances in a given field (empirically, not necessarily by/for academia). |
| --- | --- |
| **1.4** | “I didn’t go and do blood sugar tracking just so I could contribute this data for research. But if I have it anyway, I'm happy to contribute. If I knew someone doing research, it's just a little additional effort for me to capture some additional information and I'll make it useful to them. I'm The motivation could be accompanied by a mention to a specific field, discipline or area of knowledge, even critically. Also (or instead) to a personal challenge perception in a given personal research |
| **Oriented to do what (mainly) with that empirical knowledge?** | A. Sharing empirical knowledge  
B. Learning from |
Also regarding the need (or absence) of these advances, and especially how they contribute to learning, discovery or sharing with others. happy to do that, too. It gives like the experiment some additional sense of purpose. “So one of the big benefits of these projects is that you learn a lot of, it's like science, you know in school, you do science projects. The goal of a science project in school is not for you to win a Nobel Prize, making new discoveries. It's a way to kind of engage you and make you learn about things that are already known by discovering for yourself”

problem or complex topic to address. Academic scientists or doctors can be also mentioned, critically or not. Special verbs to pay attention to are “questioning”, “designing”, “observing”, “reasoning” and “discovering.”

empirical knowledge

Related approaches: Christiansen, Kristensen and Larsen, 2018; Ajana, 2017; Wolf and De Groot, 2020.

| Sharing goals and values with peers: References to perceived overall agreement, similar points of view objectives or interests, aligned judgement etc. with other individuals regarding a given self-tracking activity or research topic, tool or approach. |
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| “Something that’s exciting about Open Humans is that you can even amongst enthusiasts and amongst people who are engaged and excited about it, you can share data sets and you can share consistent data sets, it’s a medium to communicate studies and exchange data sets” // “I don’t really know how research works yet, but especially [P02] and other people in the group, we definitely seem to have a lot in common even in a standard academic place, so excited about that. I think to nerd out is the phrase which is like just be with like-minded people who think about similar problems and a kind of weird way” |
| As an inclusion criteria, it is important to pay attention here to statements using or connected to the first person of the plural (“us”, “we”, etc). It can imply somehow “socialization” too, even referred to peers or colleagues outside the community, or shared problems among patients. Also, it can refer to a mention of a new gadget or tool and peers as “early adopters”. |

| Sharing which goals or values in connection to Mertonian norms? |
| --- |
| A. Social interaction* (meet / discuss with like-minded people) |
| B. Communalitiy (community affinity / common ownership / collaborative efforts) |
| C. Universalism (inclusivity / objective validity of knowledge claims) |
| D. Organized skepticism (discussion / presenting self-research / getting feedback) |
| E. Disinterestedness (importance of own project / personal |
and individual research goals)

Related approaches: Heyen, 2016; Merton, 1973; West and Pateman, 2016.

(*) 'Social interaction' subcoding added in a second round of interpretation assigned on a consensus basis regarding this specific category.

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