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A Conceptual Framework for Personal Science

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This paper introduces a conceptual framework to guide research and education into the practice of personal science, which we define as using empirical methods to pursue personal health questions. Personal science consists of five activities: questioning, designing, observing, reasoning, and discovering. These activities are conceptual abstractions derived from review of self-tracking practices in the Quantified Self community. These practices have been enabled by digital tools to collect personal real-world data. Similarities and differences between personal science, citizen science and single subject (N-of-1) research in medicine are described. Finally, barriers that constrain widespread adoption of personal science and limit the potential benefits to individual well-being and clinical and public health discovery are briefly discussed, with perspectives for overcoming these barriers.

Keywords: quantified self, self-tracking, N-of-1, citizen science, digital health, personal science

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INTRODUCTION

The use of empirical methods for learning and discovery is a valuable human capacity. Our interest in the use of empirical methods for personal exploration was stimulated by a decade of work in the Quantified Self community. The term Quantified Self was introduced as a journalistic description of the emerging practice of using technology for self-tracking (Wolf, 2010). Prior to its first publication, however, the term was in use for several years as the name for a hobbyist group of users and makers of self-tracking tools whose participants shared an interest in "self-knowledge through numbers." The first meeting of the Quantified Self was held in October, 2008 in Pacifica, California. Participants in the original Quantified Self group met frequently and in growing numbers during 2008 and 2009. Over time, these meetings came to focus mainly on first person accounts of self-tracking projects and experiments. This focus was encouraged by "three prime questions" addressed in each talk: What Did You Do? How Did You Do It? What Did You Learn?[1] In the period between 2009 through 2019, the network of Quantified Self meetings grew to ∼110 meetings in 30 countries.

The Quantified Self community has become a focus of academic research interest in the cultural effects of new technologies (see, for instance: Lee, 2013; Morozov, 2013; Swan, 2013; Choe et al., 2014; Lupton, 2016; Neff and Nafus, 2016; Ajana, 2017; Sharon, 2017; Heyen, 2020). A key set of scholarly questions addressed by sociological researchers into the Quantified Self community relates to how the self-research activities seen in the meetings and documented in its archive of presentations can be characterized (Almalki et al., 2015; Lupton, 2016; Heyen, 2020). As one of these scholars, Nils Heyen, has recently written:

> From the perspective of science (and technology) studies and public understanding of science, these self-tracking research practices are an interesting empirical phenomenon that deserves further scrutiny. It seems that, far away from institutional science, some lay people or citizens, at least no professional scientists, use methods and procedures known from science such as research design, data collection or data analysis in order to produce knowledge for self-use in their daily lives. How can the relationship between science and society, or science and the public… be characterized here?

[1]https://quantifiedself.com/blog/our-three-prime-questions/

Building on earlier work, Heyen uses the term "personal science" to describe these self-research practices. Here, we introduce a conceptual framework for personal science, in order to guide research into this practice and support its acquisition as a skill. The features we describe as typical of personal science are analytical abstractions grounded in self-tracking practices common in the Quantified Self community.We hope our framework will be useful to scholars working on characterizing this kind of self-research, as well as to practitioners and tool makers who share our interest in advancing everybody's capacity to take advantage of empirical methods to address personal questions.

PERSONAL SCIENCE: DEFINITION, EXAMPLES, AND ACTIVITIES

We define personal science as the practice of using empirical methods to explore personal questions. Copious material exemplifying this practice can be reviewed in the public archive of the Quantified Self community, which currently contains records of 1,093 presentations, of which 508 have been transcribed and 385 have been published online.

For instance, in September, 2011, Lindsey Meyer suffered an ontologic emergency: the loss of all hearing in one ear. Later that year, she tracked the partial return of her hearing through treatment with oral prednisone and intratympanic injections of dexamethasone. She was able to both plot the improvement and, in advance of her physician, determine when the benefit was leveling off (Meyer, 2011).

In March 2012, Sara Riggare used a smartphone app for finger tapping to explore daily variations of the effects of her medications for Parkinson's disease. She was thereby able to glean important insights about her disease and treatment that could not easily have been discovered in any other way (Riggare, 2012).

In the spring of 2018, Thomas Blomseth Christiansen used a one-button instrument for recording the times he felt an itching in his nose. Using this data in combination with pictures from a GoPro camera, he was able to determine which plants caused his allergies (Christiansen, 2018).

These examples, among many other, have five kinds of activities in common as described in the following paragraphs and depicted in **Figure 1**.

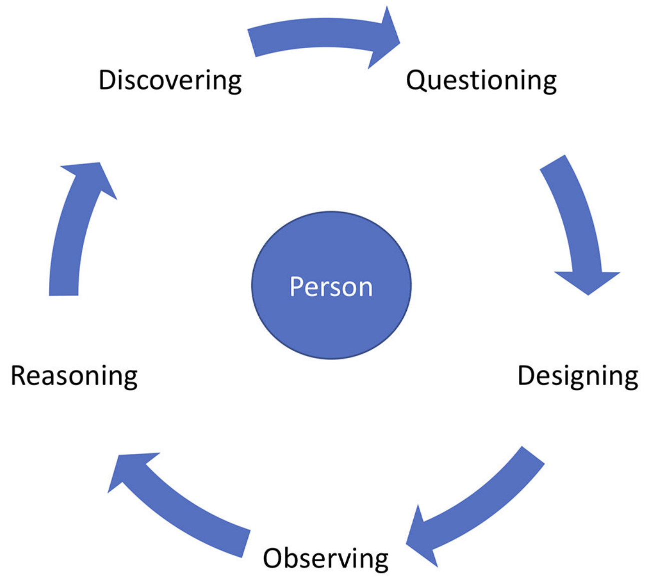

FIGURE 1 | Personal science is defined as the practice of using empirical methods to explore personal questions. This practice is characterized by five kinds of activities and begins with questioning.

Questioning

Personal science specifically addresses personal questions. We use the word personal in its ordinary language sense, pointing to questions directly relevant to the individual asking the questions, and concerning their private life, experiences, and emotions. It is the self-reflexive quality of the questions that makes personal science personal; that is, the researcher's own life is the research domain. Personal science always involves the deliberate choice of the individual about what questions to ask, what methods to use and what observations to make.

Designing

Empirical approaches vary widely in formality and complexity. Simple self-observation of a single variable across time allows self-reflection on patterns of change. More complex self-experiments with alternating conditions or interventions can reveal cause-and-effect relationships when important questions justify the effort. The design activities in personal science involve exploring, applying, and adapting empirical methods to suit the aims, needs and skills of the person involved.

Observing

Personal science uses observations made through self-tracking, which is a process of deliberately collecting and structuring observations about one's own life. Widely varying types of instrumentation can be chosen to make these observations, including medical assays, digital technology, and pen and paper. The data can represent physical, emotional, social, or environmental phenomena. Observations can be gathered actively, as when a self-tracker presses a button on a device or creates handwritten notes; or, passively, using sensors on the body or "data exhaust" from digital records associated with other devices such as mobile phones and computers. The development of personal science has been supported by digital technologies that allow the collection of detailed real-world data about individuals. However, the most important distinguishing feature does not lie in the instrumentation used for making observations, but in the control of the self-tracking process by individuals exploring their own questions.

Reasoning

The reasoning process in personal science is carried out mainly by the individual who is its main subject. Individual control of reasoning means determining what questions to ask, what methods to use, who to consult for help, and balancing risks and benefits. Approaches to reasoning with one's own data may include data exploration, analysis, and visualization, development of formal experiments, and active reflection on one's own and with the help of peers and healthcare practitioners. Records of self-observation in a project of personal science often take the form of tabular real-world data, and the reasoning process typically involves common methods of digital data analysis, such as creating time-series graphs.

Discovering

In personal science, learning occurs throughout the whole cycle. We use the word discovering to refer to specific steps of consolidation and sharing. By consolidation we mean practical actions to improve daily life and by sharing we mean public discussion and dissemination. Insights gained during this process often lead to further questions that can initiate a new cycle of exploration. Consolidation and sharing of discovery depend on having time, freedom, and power to act on what's been learned, as well as support from peers and professionals.

PERSONAL SCIENCE IN HEALTH

Motives for developing a question that lead to self-tracking projects include curiosity, the need for problem solving, the quest for improvement to health and well-being, and pleasure in tinkering and creative expression. Self-tracking projects are often inspired by an encounter with the insights others have gained through similar projects presented at Quantified Self meetings or shared on the internet. Although the skills and activities associated with empirical self-study and encompassed by the concept of personal science are widely applicable, here we focus on health for three reasons: first, health is a dominant theme in Quantified Self practices; second, many individuals attempting to address consequential personal questions using their own self-collected data depend on collaboration from health practitioners, who require clear definitions and methodological context for evidence-based practice; and, third, the greatest promise of widespread benefit from access to the tools and methods of personal science lie in the health domain.

The specific goal of a personal science project may be as simple as checking intermittent clinical measurement of key biometrics with more frequent home measurements, or as complex as assessing the effect of highly structured self-administered trials of interventions. Along with the examples described above, self-trackers in the Quantified Self community have presented projects relating to, for instance: adult-onset acne, atrial fibrillation, Crohn's disease, IBS, asthma, and headache. The value of these projects to participants are not limited to cases where medical treatment is the main concern. Self-trackers have presented personal explorations on effects of diet on sleep; progress toward sports and fitness goals; patterns in mood and stress; along with many other distinct topics.

Self-trackers presenting at Quantified Self meetings often report that their projects have been useful even when their initial question was not resolved. Ancillary benefits include deeper learning about a health topic; generation of new ideas for improving their own care; productive engagement with clinicians; and providing a sense of agency while dealing with the stress of disease and treatment. The sense of agency is noted by self-trackers across a wide range of expertise. Even individuals who are clinicians themselves, or otherwise highly trained as researchers, have described the discouraging passivity induced by the experience of illness. Reasoning about one's own conditioning counteracts that passivity. As Dr. Larry Smarr, who suffers from Crohn's disease, put it in a QS community "Show&Tell" talk in 2011: "When you get a sense of knowledge, and, if not control then at least a sense that you can understand what's happening to you—then there's hope."

PERSONAL SCIENCE AND N-OF-1 TRIALS IN MEDICINE

In the health domain, interest in addressing highly individual questions has a long history. The personal science framework reaches back to the tradition of single subject research design in applied fields of psychology, education, and human behavior, where it has benefited from extensive methodical research and practical guidance for practitioners (Kratochwill and Levin, 2010; Kazdin, 2011). However, the personal science framework and single subject research design are not the same.

Single subject research design is a scientific method in which an individual person serves as the research subject. Where single subject research takes the form of a rigorously conducted N-of-1 trial, it has high evidential value in medicine (Vohra et al., 2016). The limitations of N-of-1 trials in medicine are well-understood (Mirza et al., 2017). The urgency of acute illness offers limited time for rigorous trials, while more slowly progressing or chronic conditions require lengthy commitment to individually-focused discovery that clinical practice does not normally support (Kravitz and Duan, 2014). The aim of clinical studies of N-of-trials in medicine is to deliver results that simultaneously provide personal benefit, are clinically practical, and create generalizable knowledge that can be broadly applicable. Proponents of N-of-1 trials in medicine have the burden of showing that they improve patient outcomes in comparison to standard treatment (Kravitz et al., 2018; Mirza and Guyatt, 2018; McDonald et al., 2019).

The aims of personal science are different. As the extensive examples in the Quantified Self archive demonstrate, personal science typically involves reasoning about problems medicine often does not address: highly individual, often long term personal challenges, and questions such as finding the triggers of intermittent conditions in everyday life, understanding the effects of changes in diet and daily activities on physical and mental health, or using regular measurements to guide day-to-day decision making about sports, travel, work, and management of chronic disease. Individuals spend time and effort figuring out for themselves what they should measure that can give them insight into their question, choosing measurements that are personally relevant rather than clinically defined. For these reasons, personal science should not be understood to be identical to N-of-1 trials in medicine. Although self-trackers benefit from clinical knowledge and use it, where relevant, to guide their projects, personal science is a distinct form of empirical reasoning focused on health questions arising in daily life.

CITIZEN SCIENCE AND PERSONAL SCIENCE

In 1991, Martin and Brouwer (1993) introduced the term personal science to describe an approach to characterizing scientific practice for young students, an approach that emphasized that "science is not simply rational and objective but that the inquiring person is an integral part of the enquiry." Personal science as a concept was derived from work of noted physical chemist and philosopher of science Michael Polanyi, whose work emphasized the tacit and subjective dimensions of mainstream scientific practice (Polanyi, 1958). Although in its origin the term personal science has wide scope, it has more recently been used to refer to the kinds of self-research described here (Roberts, 2014; de Groot et al., 2017; Heyen, 2017). In a well-informed and sensitive analysis that draws extensively on research conducted in the Quantified Self community, the sociologist Nils Heyen proposed "personal science" as the specific term labeling the practice of exploring one's own personal questions using empirical methods (Heyen, 2020). The distinctness of personal science relates both to the methods of its practice and to the domain of its application. Personal science shares the same overarching empirical framework as science generally. However, the research is motivated by personal questions salient in everyday life, it's methods are typically simple, and the discoveries are applicable directly by the person doing the research.

The practice of using empirical observations to address personal questions has clear similarities to citizen science. In the mid-1990s, Alan Irwin proposed the term "citizen science" to describe active collaboration between scientists and the public to understand complex ecological challenges and develop new approaches (Irwin, 1995). In published scientific literature, most projects described as citizen science involve volunteer contributions of observations and classification of data in ornithology, astronomy, meteorology and microbiology (Kullenberg and Kasperowski, 2016). However, in recent years, the term citizen science has come to encompass a wide range of diverse approaches to involving non-professionals in research. In its most general definition, citizen science describes research in which non-professionals play an active role in funding, data collection/generation, analysis, interpretation, application, dissemination, or evaluation (Mueller et al., 2011; Prainsack, 2014).

In the practice of personal science non-professionals occupy most, if not all, of the significant roles in research. However, this approach is distinct from citizen science in significant ways. Personal science is self-directed: that is, the subject of the research is also the primary investigator. This feature is not present in the majority of citizen science projects (NAS - National Academies of Sciences, 2018). The selection of topics and questions in personal science are determined by the researcher's personal motive alone; in citizen science the questions are typically determined by the research agenda of a scientific discipline. Where personal science addresses a health question, it typically aims at a specific personal question, where citizen science aims at creating generalizable knowledge. Despite these key differences, personal science and citizen science are aligned around a common commitment to democratic participation in science (Vayena and Tasioulas, 2015).

PROSPECTS

We envision a world of personal scientists, in which everybody has access to the support that they need to address their own questions about health and well-being using the tools and methods of science. Broadening participation in personal science is needed to catalyze new discoveries at both the individual and collective level. Widespread participation in personal science primarily benefits the individuals who make personal discoveries, but it can also make important contributions to the next generation of clinical and public health studies, which depend on data gathered in daily life which, when aggregated, may allow for population-based effect estimates. Engagement in personal science strengthens the empirical foundation for discovery generally.

Three developments in digital technology have been important in encouraging the spread of personal science: access to science on the web; online community and peer support; and, digital tools for sensing and tracking. However, to make personal science widely accessible, significant barriers must be overcome. First, methods for personal science are underdeveloped. Today, practical approaches to formulating good questions, setting up a self-tracking project, and visualizing and learning from one's own personal data tend to be handcrafted by individuals as they work on their projects. Translating common features of these handcrafted methods into designs that can be easily shared and adapted for personal use by many people will lower the barrier to participation. Second, personal science depends on self-tracking tools. However, today's commercial digital self-tracking tools are not appropriate for many types of personal questions. Digital data is often not accessible to users, who face important privacy and security threats, while instrumentation for many kinds of personal questions is expensive, inflexible, or lacking altogether. Third, all learning requires social support. Support for personal science is especially needed from those health professionals most directly concerned with individual care, including nurses, physical therapists, and specialists in rehabilitation and elder care. Broad recognition of the value of personal science is needed so that individuals can find encouragement, inspiration, and education both in the healthcare system and in other domains where consequential questions arise. Finally, people doing self-research require time to make discoveries and power to act on them. In this respect, support for personal science inevitably touches on broader social issues of democratization and social change. We hope our framework is helpful in furthering this change.

DATA AVAILABILITY STATEMENT

Publicly available datasets were analyzed in this study. This data can be found here: https://quantifiedself.com/show-and-tell/.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct and intellectual contribution to the work, and approved it for publication.

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Conflict of Interest: GW is co-founding director of Quantified Self Labs (LCC, San Francisco), a social enterprise that supports the Quantified Self community worldwide since 2009. MD was (2012–2017) co-founding director of Quantified Self Institute at Hanze University of Applied Sciences Groningen. Both authors are currently associated with the Article 27 Foundation, an international non-profit network organization which aims to support personal science.