CRI Research Fellowship, Project Proposal Open health – from data-rich research to development of frugal software and hardware solutions (proposal sent on 2019/01/30)
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EXploring Collective Care in Research: A pilot-study with PhD Students (#ExCCiR-PhD)

Abstract :

Within the academic community, several studies point out that working towards a PhD is a particularly sensitive time, causing significant stress that affects the well-being of PhD students. While some actions are being implemented to support their mental and physical health, these actions and resources are still limited and no program has been designed and proposed in order to implement different individual and collective support modules.
This project aims to develop a well-being pilot-program for PhD students in a Participatory Action Research (PAR) approach in order to co-develop with all stakeholders concerned its content as well as the research protocol to assess it. The CRI ecosystem and the modules already proposed - in particular positive psycho-education and Meditation-Based Stress Reduction techniques - will be at the heart of this pilot study, which will exploit the potential of digital technologies (hardware/software) to collect social, behavioral and physiological data, in order to analyze them with open and data science practices and identify relevant markers to assess its impact.
In addition to the social and pedagogical benefits, this study proposes to explore innovative perspectives in cognitive sciences on mind/body interactions and the role of interoceptive processes in emotional regulation and indirectly on well-being. This project will adopt mixed-methods (qualitative/quantitative) with the particular aim of bringing together various disciplinary fields and stakeholders and to propose a more comprehensive reflection on the necessary conditions for the implementation of an ethics of care in the context of digital and open research.

Keywords : PhD students well-being, mixed-methods, participatory action research, interoceptive theory, digital technologies

1/ Introduction and background

“Shoemakers are the most poorly shod”. This popular expression, when applied to the world of research and health, reminds us that people or future generations who work to improve the well-being of our societies sometimes struggle to take care of their own physical and mental health and to question the conditions necessary for a quality working environment. However, the promotion of mental health and well-being is a major theme highlighted in recent years by various international organizations on global health. The Lancet Commission (2018) reminded that mental health is a crucial point in the objectives of sustainable development and results in a need for prevention and promotion of well-being but also for interdisciplinary and multi-scale research on this subject (from neuroscience to implementation science) [1]. Within the academic community, several studies point out that working towards a PhD is a particularly sensitive time, causing significant stress that affects the well-being of PhD students and their mental and physical health [2, 3]. Risk factors have been identified such as belonging to different sub-populations (women, international students, part-time jobs) or the perceived quality of supervision over their thesis. Physiological factors (quality of sleep or physical activity) also seem to play a role in the stress levels of PhD students and has an impact on their well-being [4, 5]. However, these studies highlight a lack of research on this specific population and notes the importance of setting up courses such as positive psycho-education program (e.g SPARK program) or mindfulness based stress regulation techniques (eg. MBSR program) [5, 6]. On the other hand, more systemic cultural transformations related to the

supervision of research and the involvement of "top-down" measures to promote mental health is highlighted [5, 6]. While some actions are being implemented to support PhD students in higher education institutions (HEI) (thesis advisory committee, psychological monitoring), these actions and resources are still limited and no program to our knowledge has been designed and proposed in order to implement different individual and collective support modules as well as to evaluate the influence of such a program on PhDl students well-being.

2/ Research question and hypothesis

This research project aims to answer these two exploratory questions:

> 1/ How can we build a support program for PhD students to ensure their individual well-being, both physical and mental, as well as a collective quality of life within the institutes in which they are members? 2/ What are the elements to be identified in order to evaluate the influence of such a program on the well-being of PhD students and to deploy it in different contexts?

To answer this question, we formulate three lines of research (rather than hypotheses) that are in accordance with the fundamental principles of open health. The objective is to develop a pilot support program for PhD students and a research protocol aimed at identifying a set of social, behavioral and physiological factors that will facilitate its evaluation and future adaptation.

1/ Participatory action research (PAR) and co-production of knowledge: The first strong axis is to develop a pilot program in a community-driven perspective. The investigation of well-being of PhD students is complex, involving multiple stakeholders and requires the identification and consideration of a set of relevant institutions (policy makers, doctoral school, laboratory and supervisors). Therefore implementing a PAR [7] and ethics/design [8, 9] of care would help meet the needs formulated by PhD students while taking into consideration the structural levers and obstacles highlighted by other stakeholders.

2/ Exploit the potential of assistive digital technologies: Currently, studies on PhD students well-being are based on qualitative methods (interviews, focus groups) or quantitative methods with printed questionnaires. However, future studies would benefit from integrating *open and data science* methods influenced by ongoing open health projects (Healthy Brain Network, SageBionetwork, 4youandme). We propose to collect various data assisted by digital technologies, to analyse them with data science approaches but also to guarantee the quality and reproducibility of the results in health through open science practices [10, 11].

3/ Supporting the well-being of PhD students by exploring mind/body perspectives: In the pilot program, it will be relevant to implement modules that place at the heart of their therapeutic approach the awareness of cognitive, emotional and physical patterns. These reflect recent studies in cognitive science on mind/body interactions and interoceptive theory [12]. Portable sensors are increasingly being used to understand how interoceptive processes play a role in emotional regulation and the development of some mental disorders (anxiety, alexithymia, autistic disorder) [13]. The deployment of such modules (psycho-education, mindfulness) and the collection of social, behavioral and physiological data allows for innovative research avenues that identifies bio, environmental and social markers to measure the influence of such a program on the quality of life of PhD students.

3/ Detailed project description

The project will be divided into different research phases to be conducted sequentially or in parallel with mixed-methods (qualitative/quantitative) summarized in part 4 and 5/.

1/ An inventory of research on PhD Students well-being and a review of existing support programs (Year 1: 3 months): The first part will consist of a systematic review of studies already conducted in France and abroad (meta-analysis), and their highlighted recommendations. The development of a network of stakeholders in France and abroad involved in these actions will allow the identification of ongoing initiatives in higher education and research and the classification of these activities (thesis advisory committee, psycho-education or MBSR programs, online resources, psychological support, etc.)

2/ Coordination of the stakeholders involved in the pilot program with the CRI as the cornerstone. Recruitment of the first pilot PhD students (Year 1: 6 months): The pilot study is intended to be based mainly on the CRI ecosystem. Indeed, the CRI already offers support modules for PhD students or ongoing research in open health/learning that could be integrated. A series of individual interviews, focus groups and other innovative formats (co-design sessions) will be conducted with PhD or institutional stakeholders associated with the CRI to discuss the implementation of this program and the recruitment of PhD students. The FIRE PhD Program is composed of an interesting diversity of profiles (foreign students, STM students but also SSH students through the FAN program) that can be enhanced by other PhD students from the partner institutes (cf. questionnaire)

3/ Co-design of the pilot-program and the associated research protocol (Year 1: 6 months): Once the community is established, the next phase will concern the co-design of the program such as, the modules to be included, the communication to be conducted but also the research protocol to collect and analyse data within this study. In using an open health perspective, a major point will be to lead collective reflection on the tools and data made available in order to foster mutual learning, while respecting social, ethical and legal issues (cf. survey question about ethical considerations)

4/ Development of the assistive technologies (Year 1 and 2): This phase will aim to develop the open source hardware and software to be integrated into the research protocol. This will involve collecting a set of data (social, behavioral and physiological) and analyzing them in order to identify relevant factors to assess the influence of this program. This implementation will be based on on-going projects at the CRI in order to enhance the frugal and open dimension of these initiatives and to propose other complementary fields of study (see survey). The citizen science platform developed at the CRI could potentially be included in this project. For example a range of behavioral data could be based on the Mindlogger mobile application. Physiological data could also be collected with wearable devices developed by the MatterLab, in particular for measuring the cardiac activity (ECG) required to evaluate the interoceptive awareness/accuracy. Other physiological elements (skin conductance) may be proposed following discussions/collaboration with other projects carried out at the CRI (4youandme) or with other partner laboratories.

5/ Implementation of the pilot program and co-analysis of the first results with open and data science (Years 2 and 3): Following the first year of co-design (program and its research protocol), the next 2 years will involve implementation and co-analysis. In addition to the quantitative data, a set of qualitative data will be collected with participant observation in the modules followed by the PhD students, interviews, focus groups at different key moments (end of modules, year 1 and 2). Ideally, continuing over three years would be the most relevant (average time of a PhD) but will depend on securing additional funding. The data collected will be analyzed as much as possible with the involvement of the different

stakeholders in particular PhD Students, while taking in consideration ways to avoid bias in the research protocol and the respect of personal data. This approach will facilitate research-based learning in open and data science methods and aims to develop a critical reflexivity of the results as well as at the factors influencing individual and collective well-being in research today.

6/ Writings and dissemination of the outcomes, reporting to the various stakeholders and proposal for future adaptation of the pilot program in other contexts (Year 3): This project will end with the dissemination of the main results in the form of diverse outcomes (guidelines, scientific articles, workshops). It will also involve identifying other partner institutions in France and abroad in order to test this project in other situations and implement comparisons between groups : design of the program, other student populations or other cultural context.

4/ Methods

The project is deployed in a participatory action research (PAR)[7] approach to co-construct the program with the people and community concerned while using mixed-methods (qualitative/quantitative)[14]. The project will follow an embedded mixed-method design based on a qualitative approach while integrating quantitative elements of data collection and analysis throughout the research process. The qualitative approach will be based on individual interviews, online and offline discussion groups and other innovative formats (co-design workshop, hackathon) with an analysis of materials by grounded theory. Quantitative methods will consist of collecting data through different online applications and platforms (behavioural data) and portable sensors for physiological data. This data will be analyzed through a data science iterative workflow, and free and open science practices (R or python programming language, use of a collaborative work platform for sharing algorithms, open access) promoting research reproducibility. The implementation of this research will be integrated into the principles of ethics by design to respect the integrity of the participants.

5/ Timeline

This table below summarizes the different phases of the research described in part 3 & 4..

GANT Project (#ExCCiR-PhD)	Start	Finish
1/ Meta-analysis and review of the existing network (3 months S1)	9/2/2019	12/13/2019
2/ Coordination of the stakeholders and recruitment of the pilot group (3 months S1)	9/2/2019	12/13/2019
3/ Co-design of the pilot program and its research protocol (6 months S1-S2)	1/13/2020	26/06/2020
4/ Development of the assistive technologies (6 months S1-S2)	1/13/2020	26/06/2020
5/ Implementation of the pilot program with PhD Students (1 year S3-S4)	10/1/2020	05/20/2021
5/ Implementation of the pilot program with PhD Students (1 year S5-S6)	10/1/2021	05/20/2022
4 & 5/ Co-analysis of the results, improvement of the technologies (1,5 years S3-S6)	10/1/2020	12/1/2022
6/ Writings feedback and recommendations, dissemination of outcomes (6 months S6)	06/01/2022	08/30/2022
6/ Development of future program and its adaptation (6 months S6)	06/01/2022	08/30/2022

6/ Match between the researcher and the project

This project combines the skills that I acquired (Célya Gruson-Daniel) in 1/ my initial course in biology (undergraduate) then in cognitive and behavioural neurosciences (postgraduate) at ENS, UPMC and USCF (cv. CV) 2/ the theoretical knowledge on open science developed in my doctoral research [15] at CRI in the field of Science and Technologies Studies 3/ my commitment to PhD students with the HackYourPhD community and my daily open science practices and experimentation 4/ my transversal skills in the use of digital technologies in research and education (open and data science project management, coordination of a MOOCFactory). I will develop this research project rooted in collaborative practices and mutual sharing of knowledge and expertise by relying on an established network of senior researcher and other professionals (open science, public health, neuroscience, meditation). I see my role as a researcher and as a mediator to bring together disciplinary fields (cognitive science, social sciences, data science) and various stakeholders (institutional, health professionals, public policies) and create a collective reflexivity on the necessary conditions for the implementation of an ethics of care in the context of digital and open science.

7/ Originality, innovation, and interdisciplinarity

In addition to open and community-driven approaches used to understand and promote well-being in research, this project is grounded in a meta-research perspective to foster open learning and phronesis at the heart of research and education ecosystem. Participants will be able to question their own biases concerning their visions of (open) science and their role as researchers, students, etc. today. This initiative also aims to explore interdisciplinarity at the interfaces of Life, Digital and Learning sciences through a dialogue and experimentation between different research paradigms (hypothetico-deductivist/constructivist). The originality of this project is also based on a strong conviction to consider openness as an open-mind “thinking outside the box” to create societal but also economic and political innovations grounded in the theory of the commons [15] and an ethics of collective care [8].

8/ Main challenges and potential pitfalls

One of the difficult aspects of this project will be to communicate sensitive issues related to well-being, that is to say controversial or even taboo topics such as mental disorders, burn-out and high competitiveness and pressure that crosses the academic world both on an individual and a collective level. Building a network of various stakeholders in time and dealing with institutional blockages or inertia will be one of the main challenges in terms of time management. A fair balance will also have to be developed between research integrity, ethics and policy and the involvement of stakeholders in data analysis. This project, with its dimension of co-design and its qualitative approach with a systemic aim, will nevertheless anticipate possible obstacles and their solutions.This initiative will also rely on the advice and previous experience offered by the CRI ecosystem. Even if the pilot-program might encounter limitations, the collection of a diverse range of data at different stages of the research will lead to concrete results that will allow for a collective understanding on how to foster well-being in PhD studies as well as the implementation of open health projects.

9/ Budget

BUDGET (in €)	Year 1	Year 2	Year 3	Justification for expenditures
1- Equipment and Supplies				
1-1 General IT	5000			Computer, smartphones, hard disk for the team
1-2 For data collection				
1-2-1 Digital technologies for quantitative research	5000			Assistive technologies : android, wearable/mobile devices, web-based platform
1-2-2 Costs and supplies for qualitative research	5000	5000	5000	Supplies for interviews, focus group, workshops + Legal advices
1-3 For data entry and analysis	1000	1000	1000	Open source software freemium, servers, data storage
1-4 For dissemination				
1-4-1 Publications costs		1500	1500	Open access journal cost
1-4-2 Graphic design	1000	1000	1000	Communication (logo, pedagogical graphics, etc.)
2- Personnel services				
2-1 Hardware engineer/Data scientist	30000	40000	40000	Hardware engineer (1st year), Data scientist (2 other years)
2-2 Master student interns	5000	5000	5000	Design (3 months/y),Data science/hardware (6 months/y)
3- Travel, conferences and training	5000	5000	5000	Travel (networking, conferences) + Specific trainings for the team (psycho, data science)
TOTAL (per year)	57000	58500	58500	**TOTAL BUDGET (3 years): 174 000**

In addition to research budget, in the CRI research fellowship call, 1.5 person/year will be funded

10/ Speculation

In addition to the impacts mentioned in the survey, this research, although aimed at the doctorate, is part of a more global reflection on the ethics of care within the research community. This project will potentially show that through a change in the mentality of future generations of young researchers longer-term transformations (supervisory relationships) can be thought-out. This initiative would provide concrete solutions to social, pedagogical and economic challenges in research and higher education with adapted feedbacks to the different stakeholders. It also opens up, from a fundamental research perspective, questions on the cognitive, emotional and bodily mechanisms that contribute to individual and collective awareness allowing for the development of sustainable digital societies.

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Answers to the questionnaire CRI Research Fellowship

Please consider and discuss any ethical considerations that may arise from the project and how you plan to address them. This could include, but is not limited to collecting any personal information and medical data, working with humans or animals, as well as the potential effects and outcomes of your work. (100 words)

Ethical considerations and solutions are embedded elements of this project. Indeed, the well-being and mental health of PhD students is a sensitive topic and needs specific attention. Stakeholders involved in this pilot-program should be reassured that the ethical and legal rules will be respect. This includes giving them confidence that their participation will not threaten the future careers of PhD Students, as well as the reputation of Higher Education Institutions (HEIs). This is one of the reason this program is grounded in "ethics by design" principles to tackle different issues (communication, data collection and analysis, dynamic consent).

What is the expected impact of your project (fundamental, social, pedagogical, applied, entrepreneurial, etc.) ? (100 words) *

This Participatory Action Research (PAR) project is adapted to develop direct actions with strong social impact: improves the well-being of PhD students and builds an ethics of care in research and higher education. This project will be developed in close interaction with pedagogical team. Economic impact will be indirectly achieved because mental and physical health impact the quality of research and its efficiency. This project has a strong fundamental research perspectives by participating in the field of cognitive science, implementation science as well as science and technologies studies in order to improve transversal and interdisciplinary approach in open health research.

Have you secured or are applying for other financial support for your project? (100 words) *

Since July 2018, I have had discussions about this project with different CRI individuals (research fellows, Health Lab, PhD program team) as well as the HackYourPhD community. My goal is to create a collective dynamic to secure or apply to other financial support while integrating reflection about an economic model grounded in social solidarity and the commons economy. At the same time, I have already met potential partners (Pasteur Institute, Centre Virchow-Villermé). In the next months, my objective would be to open this proposal as a pre-print to a broader audience to get some feedback for potential private/public partnership.

Project - interactions with CRI : How do you envisage to interact with and contribute to the CRI pedagogy ecosystem (spanning from pre-school outreach, to undergrad, master and PhD programs, and life-long learners ? (150 words) *

This project would be designed in close interaction with the CRI pedagogical ecosystem (FIRE Program and Ecole de recherche Interdisciplinaire de Paris) since the project will include the CRI as a core element for the development of this pilot-program. Using open science and learning approaches, communication, events or courses would be organized along the project for the CRI ecosystem (Labs, research fellows but also undergraduate and postgraduate students). Moreover, for the PhD Students (or master students in internship) participating in this PAR will give them the ability to discover open science/health methodologies as well as developing their critical thinking about research and it socio-political stakes (ethics, integrity). This reflection about research and education will participate in open learning and phronesis discussion led at the CRI.

List up to three people from CRI research network* you would like to interact with and tell us why (150 words)

I have already discussed with Anirudh KrishnaKumar (CRI/MatterLab) about the possibility of using the mindlogger application and other devices developed by the Matter Lab at the Child Mind Institute. Based on his CRI outreach program in Chennai, we also conversed about the possibility of adapting this pilot program in India to explore the influence of cultural context. I would like to exchange more with Roberto Toro about the open health platform for citizen science that he is designing. His project would help to coordinate the community-driven interactions for this pilot-program. I have yet to meet with Aida Bafeta, but the perspective she is developing between open learning/serious game and research integrity could give innovative modules to integrate into the program.

List other potential project collaborators (individuals, labs, companies) in Paris, France, or abroad, and briefly describe the nature of their contribution (150 words)0/150

The asterisk index mentions people/institutions I'm already in contact with. 1/For the implementation of this program in France with Higher Education Institutes : FIRE Program* (CRI)/USPC and the CFDip/ Marina Caillet* (project manager of the inception program at Pasteur Institute)/ Marc Barbier* (director of Institut Francilien Innovation Societé)/Jean-Charles Caillez* (Director of HEMiSF4iRE at Université Catholique de Lille). 2/ For the development of wellbeing modules : Health Lab at CRI with Olivier Bory and Cloé Brami* (MBSR Program)/Pascal Haag (BESTDOC course coordinator and psychologist)/ Antoine Flahault* (Director of the Institute of Global health at Geneva)/ Anneliese Depoux* (Director of the Centre Virchow-Villermé). 3/ For fundamental research in cognitive science : GuillaumeDumas* (researcher at Pasteur Insitute)/ Maddalena Cana* (post-doc at Northwestern University, member of the ALIUS). 4/ For open and data science approaches : DRISS*/HackYourPhD community*/La Paillasse*/ Florence Piron* (APSOHA, Université Laval)/ Healthy BrainNetwork/SageBionetwork/4Youandme

What specific equipment or support would you need for your project? (100 words) *

Specific equipment needed would be mainly digital equipment which required 1/ web and UX design development for the mobile applications and web-based platform (behavioral and social data) 2/ Maker lab for the open source hardware and the development of portable open devices (physiological data). Other general IT would be necessary as computers, hard disks but also dedicated servers and data storages. Support needed would be from designer, open hardware engineers, data scientists but also psychologists, meditation trainers and lawyers for legal and ethical considerations (cf. Budget in the Project Description).

Total amount of budget requested for the entirety of your fellowship stay (in euros) *

The total amount of budget requested for 3 years is 174 000 euros. The detail budget is available on the project description and also online here : https://docs.google.com/spreadsheets/d/1xyd-DrfTjKFYQI3y0END_OGflKh_NPOB4_Vq7-VTDEo/edit#gid=0

Beyond the time at CRI : How will you personally benefit from your time at CRI Research? (150 words)

The CRI (as a former PhD Student) has been already a wonderful place for me to incubate research and education projects grounded in societal and care values. It is a place that I feel comfortable, understood and at home but also driven to think and create projects combining my background in biology and cognitive neurosciences, my practical expertise in open science and other professional skills. This research Fellow will help make the last 10 years of work and exploration about open science in France and abroad a reality, while keeping in mind the complex ecosystem where we are living. Indeed, this project will allow me to continue the work I have done during my PhD in social science and put into action the analysis I have made relating to the conception of open science and the necessity of mediation to alleviate frictions between research fields in Science today.

How will your project continue after you leave CRI? (150 words)

This project is integrated in Open and FAIR (Findable, Access, Interoperability and Reuse) principles for all its components. An important part will be to document all the steps of the project to create a pilot program that is reusable. The development of an open and data science protocol to collect and analyze social, behavioral and physiological data with the use of open source and frugal hardware and software will facilitate its implementation and adaptation. During these three years, I'm eager to benefit from the

international CRI ecosystem to propose and test this program in other cultural context and with other partners. I hope this program will be adapted for other population (undergraduate and postgraduate students) but also in complementary studies (using psycho-education or mindfulness program) in the field of global mental health and well-being prevention for our societies.

General interests and past work : Describe briefly one research project you have done so far. (200 words)

The #MOOCLive project (IDEFI-N) highlights specifically the utility of my interdisciplinary knowledge (from cognitive sciences to humanities and social sciences) and other intersecting skills that I acquired with my professional experiences (open and data science management, MOOC coordination, research funding, scientific communication). This project was led by the Centre Virchow-Villermé and other partners in the field of global health and data sciences. I contributed to the writing application for this three year project (1150K euros). I then became the research project manager in order to study the MOOC participants' behavior using data science and machine learning. I coordinated an interdisciplinary team : data scientists from the company ANEO, pedagogical engineers and social scientists. The big challenge has been to create an interface and translation between these team sharing different theoretical and technical background. We designed a project to identify MOOCs learners profile based on a mixed-methods (qualitative/quantitative) with the support of active learning and markov Decision Process for behavioral inference. This project also included reflections on ethical and legal issues related to open science and digital technologies in order to consider personal data protection, data storage, open access of articles and algorithms for a reproducible research.

5 keywords that describe your research interests Open and digital science, interdisciplinarity, well being, participatory action research, meta-research

Attribution :
This document (version 1) was written by Célya Gruson-Daniel and has been proofread by HackYourPhD members (Guillaume Dumas, Matthieu Le Chanjour, Jean-Baptiste Bohuon), Clément Epié and Amelia Robertson.

Other open science comments : A specific Zotero collection #ExCCiR in the HackYourPhD groupe has been created. You will find online here the budget and the GANT project as well as the description project. I'm planning to publish this proposal as a pre-print (Zenodo or Open Science Framework) and use in the future other free software applications rather than Google apps.