The Issue 2025

Health Experiences International

MEETING IN BRANDENBURG

Methodology

Member Updates

Treasured colleagues,

The HEXI chair role has now rotated to Alicia, who is already hard at work on behalf of us all. I have seen Alicia's inclusive, sensitive and smart leadership of DIPEx Brazil, so I know from firsthand experience that we are in excellent hands. Welcome as well to Tori, our new vice chair, and Lucia, our new secretary. HEXI is flourishing!
Relieved of official duties, I can dedicate my last newsletter note as a HEXI officer entirely to gratitude. Thank you, everyone, for trusting me to act as your chair for the past four years. In a world troubled by dysfunctions more prevalent than ever, HEXI is an island of sanity, learning, conviviality, playfulness, and purpose. Our ability to come together across geographies, languages and cultures, united around our shared purpose – this touches me so deeply. And inspires me, every day, to do my part by showing up curious, brave (not always easy!), and ready to listen. I look forward to many more years of shared adventures with you, and to on-going service in the HEXI community as a proud and grateful member.
With very warmest wishes and a heartfelt "namaste,"

Rachel

HEXI INTERNATIONAL MEETING

Brandenburg 2027

Presented to you by TEAM DIPEx GERMANY

further details coming soon

MHB MEDIZINISCHE HOCHSCHULE BRANDENBURG

Methodology piece

By Rachel Grob

This brief document is offered as a way to get us all thinking, ahead of our November 4th BOD meeting, about how we might want to be referring to our shared methodology now that we have changed our name from DIPEx International to Health Experiences International (HEXI). It was drafted by Rachel, your Chair, and reviewed by the other officers prior to being sent out to the rest of you.

Background
The HERG group at Oxford (now MS-HERG) has never officially referred to the methodology shared by members of HEXI as "the DIPEx Methodology." However, many of HEXI's members around the world have been in the habit of referring to our approach as "the DIPEx methodology," and many of us have used this shorthand as a way of differentiating what we do from what other qualitative methodologists may do; of pointing out that our approach is adopted around the world and has an associated global learning community; and of signaling commitments to (among other things) maximum variation sampling, on-going consent opportunities for participants, and public dissemination of results. These references to "the DIPEx Methodology" are in many country-specific grant applications and papers, and in some international publications as well. For example, the 2020 "polyphonic voices" article reflecting on two decades of the DIPEx project refers multiple times to "the DIPEx research approach."

Current Questions for Discussion
Now that our organization no longer has the word DIPEx in its name, it may be time – as discussed briefly in Norway – to develop some guidance for our community on how to refer to our methodology such that it links to our current rather than former name. Such guidance would of course be non-binding; HEXI members are free to refer to their work in the ways that are most strategic and appropriate in their own contexts. However, signaling how we, HEXI's BOD, advise those interested in referring to a unifying methodology around which our organization is organized also seems important to do. Questions we thought about that arise as we develop this guidance include the following – and we are sure all of you will think of other questions (and answers!) too.

Should we, as discussed a bit in Norway, refer to our methodology as "the HEXI methodology"?

If we go with "the HEXI methodology," how shall we write out our acronym?
HEXI? HExI? Other?

Are we concerned to differentiate our methodology, standing for "the Health Experiences International Methodology," from the "Health Experience Insights" website which is now Oxford's platform for public dissemination of their HEXI studies? One thing to consider is that the Health Experience Insights site abbreviates as HEXI... so, perhaps we do our acronym a different way?

Thanks for reading everyone; we look forward to a robust conversation at the BOD meeting on November 4th, and to any thoughts you would like to send along on this email thread before then.

Sections and key references for papers using the HEXI methods

By Sue Ziebland

When submitting articles to peer reviewed journals we describe our methods of sampling, data collection and analysis using conventional references for qualitative methods.

In the UK group we have avoided using phrases like ‘ we collected interviews for a health experiences website’ because this has sometimes confused reviewers. The HEXI methods are not explicitly published anywhere (our Handbook is an internal document) although there are some useful references from International group members which are appended below.
The requirements of journals differ but below we include three examples of the METHODS section of articles which how one might refer to our methods, with and without explicit reference to the online platforms.

Example 1
‘further analyses can be found on …)
Ziebland S, Chapple A, Evans J. Barriers to shared decisions in the most serious of cancers: a qualitative study of patients with pancreatic cancer treated in the UK. Health Expect. 2015 Dec;18(6):3302-12. doi: 10.1111/hex.12319. Epub 2014 Dec 11. PMID: 25496598; PMCID: PMC5810685

Methods: The data discussed in this article were collected for a study of patients' experience of pancreatic cancer. With approval from The Berkshire Research Ethics Committee (09/H0505/66), we invited people to be interviewed about their experience of pancreatic cancer. Volunteer packs were distributed via five consultants and a nurse in different parts of the UK. We also distributed packs via our advisory panel, which included people from Pancreatic Cancer UK and The Pancreatic Cancer Research Fund. A few packs were distributed via general practitioners. Packs included a letter, an information sheet, reply slip and return envelope; those wanting to know more about the study contacted the research team. Some people were also recruited via an advertisement in The Metro (a free London newspaper), personal contact and the snowball method. We aimed for a maximum variation, purposive sample, to include both men and women, from different social backgrounds and ethnic groups, and different parts of the UK. We wanted to capture a diverse range of experiences, including people in different age categories, some who had been diagnosed recently, others who were in remission, and others receiving palliative care (see Table 1 for details).

People were interviewed during 2010–11 at a place the participant chose (usually at home) for between 40 min and 2 h. Having signed a consent form, people were asked to talk about their experience of pancreatic cancer; they were told they could pause, or end, the interview at any time. In the first, narrative section of the interview, respondents were asked to relate, in their own words and at whatever length they chose, what had happened to them from the time when they first noticed symptoms. When the narrative was finished, a semi-structured interview guide was used to explore any potentially relevant issues that had not already emerged, such as patients' recollection of information given to them by their doctors or how decisions were made.

The interviews were all audio-recorded, fully transcribed, checked and then returned to the participants so that they could read the text if they wished and remove or clarify sections if necessary. Data collection continued until we had interviewed people who had had a wide range of treatments, including various types of surgery, radiotherapy, CyberKnife treatment, chemotherapy, biological therapies, vaccine injections, complementary therapies and palliative care.

After 32 interviews, we felt that we were approaching 'data saturation'. Pseudonyms are used throughout this paper.

The authors read and re-read the data from all the interviews and constructed a coding frame. A qualitative interpretive approach was taken, using modified grounded theory (informed by a detailed literature review) combining thematic analysis with constant comparison.
Glaser B, Strauss A. The Discovery of Grounded Theory. New York: Aldine Publishing, 1967. [Google Scholar]
Smith K, Biley F. Understanding grounded theory principles and evaluation. Nurse Researcher, 1997; 4: 17–30.

QSR N6 (a qualitative data-indexing package) facilitated the analysis. We grouped extracts from the interviews with relevance to a number of anticipated and emergent themes; all authors discussed coding and interpretation of results. Several further analyses and many more extracts from the interviews can be found on the website www.healthtalk.org.

Example 2 – BMJ Open article, without mention of HT/HEXI
MacLean A, Wild C, Hunt K, et al. Impact of Long Covid on the school experiences of children and young people: a qualitative study. BMJ Open 2023;13:e075756. doi:10.1136/ bmjopen-2023-075756
Methods: This paper draws on narrative interviews undertaken to improve understanding of the experience of LC in households with CYP from diverse backgrounds. In this analysis, we draw on interviews with CYP (aged 10–18 years) with LC and parents/caregivers of CYP (aged 5–18 years) with LC, some of whom had LC themselves.

Patient and public involvement
An advisory panel, including patient and public involvement representatives with lived experience of LC or of caring for a child or young person with LC, had input into all aspects of the study conduct, including content of the interview topic guide and recruitment methods.

Recruitment and sampling
Recruitment routes included social media, LC support groups, clinicians, community groups and snowballing. We aimed for maximum variation sampling,29 to capture diversity by age, gender, ethnicity, geographical location and social class. Potential participants were eligible if they, or the person they cared for, had self-identified ongoing symptoms 12+ weeks after initial COVID-19 infection. CYP were eligible if they were 10 years or over. Parents were eligible if their child with LC was 5 years or over. Age-appropriate information sheets were provided to potential participants.

Data collection
Narrative interviews (n=37) were conducted (between October 2021 and July 2022) via online video call or telephone, and were video and/or audio recorded, depending on participant preference. Verbal consent was recorded at the start of their interview. Those under 16 years gave assent and their parent/caregiver gave proxy consent. Participants were offered a £30 voucher to thank them for sharing their time and experiences. Interviews began with an open narrative where participants were asked to recount events since they/their child first experienced signs of COVID-19. The second part used topic guides (different for CYP and parent interviews) with prompts, including questions about how LC had affected school (see online supplemental file 1). Interviews typically lasted between 25 and 90 min, with some conducted over multiple shorter sessions to accommodate participant fatigue or other symptoms.

Data analysis
Interviews were transcribed verbatim, checked for accuracy and imported into NVivo (March 2020 version) to aid organisation and coding of data. We used thematic analysis30 to inductively code the data. After initial familiarisation with transcripts, we developed a coding framework of broad themes, which was refined throughout the coding process. Three researchers coded the transcripts (CW, ZCS and SN). All data coded to the broad 'school/education' theme were then further analysed (by AM) using the mind-mapping 'one sheet of paper' technique.

31 This process generated three subthemes, as described below with interview extracts (IE) to illustrate the range of views (longer extracts are presented in boxes 1–3). All names are pseudonyms. When quoting a parent who spoke in their child's interview, we use the convention 'mother of Gemma (16, LC 19 months)'.

Ethics
Ethical approval was granted by Berkshire Ethics Committee (12/SC/0495).

Example 3 Sociology of Health and Illness, with explicit mention of HT/HEXI
Hunt, K., Maclean, A., Locock, L., O'Dwyer, C., Nettleton, S., Ziebland, S., & Wild, C. (2024). Young adults' experiences of biographical retrogression whilst living with long COVID. Sociology of Health & Illness, 46(8), 1526–1546. https://doi.org/10.1111/1467-9566.13798
Methods : Participants were young adults, who became ill with long COVID aged 18–30 years, sub-sampled from two linked UK studies—one on long COVID in adults (CSO—COV/LTE/20/04) and the other on the impact of long COVID on families (NIHR COV-LT2-0005). Whilst definitions of 'young' adulthood are somewhat arbitrary and vary, culturally and historically, here, we have broadly followed the definition used in recent UK studies of chronic illness at this life stage (Polidano et al., 2020; Saunders, 2017).

Data collection and sampling
Ethics approval was granted by Berkshire Ethics Committee (Ref 12/SC/0495). Interviews (n = 15) contributing to this analysis were undertaken online between May 2021 and July 2022. Sampling within the 'parent' studies aimed for maximum variation (Coyne, 1997), including diversity by region, occupational social class, ethnicity, gender and age. Table 1 shows their ethnicity and employment status and their age at (and date of) interview and when first ill with COVID-19. Six identified first being ill with COVID-19 in the first quarter of 2020 and three in the last quarter of 2021. Participants all discussed their experiences from the time they first identified as having COVID-19 up to the time of their interview. Some remained incapacitated by their symptoms, and none had returned to their state of health pre-COVID, although a minority detected some potential signs of improvement. All interviews were conducted by health social scientists with extensive experience of qualitative research.
Recruitment routes included social media, clinicians, support groups and snowballing. Interviews were audio/video-recorded according to participant preference and typically lasted 60–90 min (range 50 min to 3.5 h); some were conducted over multiple sessions if the participant preferred (e.g. due to fatigue). The first part invited participants to relate their narrative about how they became ill and how long COVID had affected their lives. The second part used semi-structured topic guides. Recordings were transcribed verbatim. Participants could review their transcript and indicate any sections they wished to be removed and choose whether they wished to be referred to by a pseudonym or their own name in study outputs.

Data analysis
Transcripts were checked for accuracy, further de-identified (e.g. removing place names) and imported into specialist computer software (NVivo) for organising textual data for coding/analysis. Discussion amongst the authorship team continued throughout data collection and analysis. In a multistage analytical approach, the interviews were first independently analysed and coded by experienced qualitative researchers using a thematic approach for each study.
Predominant themes which structured participant experiences were identified and discussed amongst the authorship team and the advisory groups of the constituent studies (which included people with lived experience of long COVID) (see www.hexi.ox.ac.uk/Long-Covid-in-Adults and www.hexi.ox.ac.uk/Family-experiences-of-Long-Covid for details on predominant themes).

Second, iterative author discussions around biographical disruption led to a decision to focus on young adulthood, as young adults had received little attention in articles on long COVID. The transcripts for the young adults were repeatedly revisited and recoded (by KH) using the theoretical lens of biographical disruption. Refinements to the approach and the line of argument were informed by further discussions amongst the authorship team, which included qualitative sociologists of health and illness who were familiar with the evolution of the concept of biographical disruption and a lived experience co-author; emerging literature on experiences of long COVID; and relevant papers on various manifestations of the concept of biographical disruption. Interview extracts were selected to illustrate key themes.

Useful refs for our approach

ZieblandS, McPhersonA. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). Med Educ. 2006;40(5):405–14. https://doi.org/http://dx.doi.org/.http://dx.doi.org/10.1111/j.1365-2929.2006.02467.x.21.

Spitale G, Glässel A, Tyebally-Fang M, Mouton Dorey C, Biller-Andorno N. (2023). Patient narratives - a still undervalued resource for healthcare improvement. Swiss Med Wkly.30;153:40022. doi:10.57187/smw.2023.40022. PMID: 36787439

Ziebland S, Grob R, Schlesinger M. Polyphonic perspectives on health and care: Reflections from two decades of the DIPEx project. Journal of Health Services Research & Policy. 2020;26(2):133-140. doi:10.1177/1355819620948909

Rai T, Dowrick A, Qureshi K, Munro H, Wild C, Douglas J, Ziebland S. How should we do racially just research? Learning from a qualitative study on COVID-19 pandemic experiences in the UK. Journal of Critical Public Health. 2024 Jun 19;1(2).

Ziebland, Sue; Sakuma Sato, Rika; Grob, Rachel; Dowrick, Anna; Navarro Dias de Souza, Alicia Regina; Spitale, Giovanni; Schlesinger, Mark (2024). Cross country analysis of qualitative interviews: Developing a method, a community and an understanding of how Covid has been experienced around the globe. SSM – Qualitative Research in Health DOI: https://doi.org/10.1016/j.ssmqr.2024.100396

Healthtalk Australia

By Lorraine Smith

2024 and 2025 has seen some exciting changes to the governance of Healthtalk Australia (HTA). Founding Directors Renata Kokanovic and Lorraine Smith have stepped aside to welcome a new team of Co-Directors, who, jointly, will guide future activities and organisational processes of HTA. Our new Co-Directors are: Tamara Borovica (RMIT), Nicholas Hill (University of Melbourne and PLACE Australia), Katie Kenny (University of Sydney), Sophie Lewis (University of Sydney) and Rebecca Olson (University of Queensland) (https://www.healthtalkaustralia.org/our-people/). Renata and Lorraine remain as advisors and mentors.

The new team (L-R): *Tamara Borovica, Sophie Lewis, Rebecca Olson, Nicholas Hill, Katie Kenny.*

HTA also has two new projects on the go. The first one is Growing Up Well. This study has been funded by the Australian Research Council Linkage Projects Scheme and will explore young people's experiences of growing up with a chronic illness. Our industry partners are Epilepsy Action Australia and Asthma Australia. Project lead is Sophie Lewis. We are currently recruiting young people (aged 16-24 years) with epilepsy and/or asthma to our Co-Design Committee to help us fine tune the data collection methods and outputs for this study. We hope to include an arts-based methods and repository in this study.

Our second HTA project is The Cost of Living (Well): A Sociological Study of Cost and Value in Health and Care. This study has also been funded by the Australian Research Council Linkage Projects Scheme and will systematically document the extent and consequences of the costs of care – financial and otherwise, and identify the structural and cultural drivers of out of pocket-induced harms. This project will also employ a co-design element, with outputs including informational, educational and advocacy resources to guide better cost-of-care conversations and inform Partners Organisations' advocacy efforts. The industry partner for this project is Carers NSW. The project is being led by Katie Kenny.

Finally, Lorraine and Sophie are collaborating with colleague Stephen Hughes (lead investigator) and his honours student (Shin Yi Yeong) on a secondary analysis of women's experiences of severe asthma. This project is drawing on our past HTA project on severe asthma. We are (re)analysing the transcripts of all the women who took part in this project through a capabilities approach lens (specifically, that advocated by Vikki Entwistle from Aberdeen University).

Interesting fact: in Australia, the greatest proportion of deaths from asthma are in women aged over 45 years. There is little known about the factors associated with this statistic, and very little published worldwide focusing on women's experiences of asthma.

Happy reading and best wishes from the Healthtalk Australia team!

Healthtalk Australia

By Lorraine Smith

2024 and 2025 has seen some exciting changes to the governance of Healthtalk Australia (HTA). Founding Directors Renata Kokanovic and Lorraine Smith have stepped aside to welcome a new team of Co-Directors, who, jointly, will guide future activities and organisational processes of HTA. Our new Co-Directors are: Tamara Borovica (RMIT), Nicholas Hill (University of Melbourne and PLACE Australia), Katie Kenny (University of Sydney), Sophie Lewis (University of Sydney) and Rebecca Olson (University of Queensland) (https://www.healthtalkaustralia.org/our-people/). Renata and Lorraine remain as advisors and mentors.

The new team (L-R): *Tamara Borovica, Sophie Lewis, Rebecca Olson, Nicholas Hill, Katie Kenny.*

HTA also has two new projects on the go. The first one is Growing Up Well. This study has been funded by the Australian Research Council Linkage Projects Scheme and will explore young people's experiences of growing up with a chronic illness. Our industry partners are Epilepsy Action Australia and Asthma Australia. Project lead is Sophie Lewis. We are currently recruiting young people (aged 16-24 years) with epilepsy and/or asthma to our Co-Design Committee to help us fine tune the data collection methods and outputs for this study. We hope to include an arts-based methods and repository in this study.

Our second HTA project is The Cost of Living (Well): A Sociological Study of Cost and Value in Health and Care. This study has also been funded by the Australian Research Council Linkage Projects Scheme and will systematically document the extent and consequences of the costs of care – financial and otherwise, and identify the structural and cultural drivers of out of pocket-induced harms. This project will also employ a co-design element, with outputs including informational, educational and advocacy resources to guide better cost-of-care conversations and inform Partners Organisations' advocacy efforts. The industry partner for this project is Carers NSW. The project is being led by Katie Kenny.

Finally, Lorraine and Sophie are collaborating with colleague Stephen Hughes (lead investigator) and his honours student (Shin Yi Yeong) on a secondary analysis of women's experiences of severe asthma. This project is drawing on our past HTA project on severe asthma. We are (re)analysing the transcripts of all the women who took part in this project through a capabilities approach lens (specifically, that advocated by Vikki Entwistle from Aberdeen University).

Interesting fact: in Australia, the greatest proportion of deaths from asthma are in women aged over 45 years. There is little known about the factors associated with this statistic, and very little published worldwide focusing on women's experiences of asthma.

Happy reading and best wishes from the Healthtalk Australia team!

Brazil

By Marcelo E. P. Castellanos

New module - COVID-19: Healthcare professionals working in Primary Health Care

In 2024, we finished a new module on Primary Health Care (PHC) professionals who worked on the front lines during the COVID-19 pandemic, based on 40 interviews. The interviewees included family and community physicians, nurses, and community health workers from the cities of Botucatu (São Paulo) and Rio de Janeiro, who shared their experiences and the challenges they faced while providing care to the population during one of the most critical phases of the pandemic.

The diverse educational backgrounds of these professionals, who worked in health units located across various regions of both cities, offered a broader and more nuanced perspective on the lived experience of the pandemic. Their narratives reveal multiple approaches to work organization, care strategies, and the emotional impact involved in confronting the public health crisis, underscoring the essential role of PHC.

The module was developed by Alicia Navarro de Souza, Antonio de Padua Pithon Cyrino, Rayssa Abreu Borges, and Laura Naggiar Giovanoni. The research team is currently analyzing the collected data for the production of scientific papers.

Available at:
http://www.narrativasesaude.ccs.ufrj.br/covid-19-aps-introducao/

New module - Heart transplantation

This module brings together the experiences of 39 individuals diagnosed with End-Stage Heart Failure who received heart transplants (or double heart and kidney transplants) at the Professor Fernando Figueira Institute of Integral Medicine, in Recife, Pernambuco. These participants come from the Northern and Northeastern regions of Brazil, representing a diverse range of socioeconomic backgrounds. Whether from urban centers or rural areas, all faced significant challenges to reach this referral center, which is fully dedicated to the SUS (Brazilian Unified Health System). Through SUS, the Institute provides some of the most complex medical procedures, as well as comprehensive pre- and post-operative care and ongoing clinical follow-up after transplantation.

Participants received the transplant at least one year ago, and the surgery took place when they were between 8 and 64 years old. The causes of heart failure are varied, from the rare Familial Hypertrophic Cardiomyopathy to Chagas Disease, endemic in Brazil and listed as a neglected disease by the WHO. They address a variety of topics, from the diagnostic pathway to transplant referral, the difficulties encountered in the hospital and after transplantation surgery, and the challenges of reintegrating into life as a transplant recipient, which requires significant personal, emotional, and life-path readaptation. These inspiring stories offer a deeper understanding of the world of individuals who need a heart transplant through the first-person accounts presented in this module.

EXTENSION PROJECT

In 2024, the Health and Care: Sharing Stories Extension Project was formally approved by the Federal University of Rio de Janeiro (UFRJ). University extension serves as a vital mechanism for connecting academic knowledge with society. Within this project, affiliated with DIPEx Brasil, we recognize that the website's content will facilitate knowledge exchange by presenting diverse personal experiences. These narratives are shared by individuals who live with similar health conditions but differ in age, race, gender, educational background, and socioeconomic status.

Undergraduate students play an active role in the project, engaging closely with research activities while contributing to the development of the website modules—editing, curating, and preparing video materials. Although the education of health professionals often includes practical components, it remains predominantly disease-oriented, with patients frequently being regarded as mere representatives of specific pathologies. Engagement with the project's modules offers students and professionals an opportunity to enhance the quality of care through a person-centred approach.

Moreover, participation in the project encourages the production of academic works presented at university events. In doing so, students disseminate not only the research conducted within DIPEx Brasil but also underscore the broader importance of recognising individuals' lived experiences of illness and care.

PRESENTATIONS 2024

Formação do Profissional de Saúde via Extensão: Experiências de Graduandos com Participação na Metodologia Dipex (Health Professional Training through Extension: Experiences of Undergraduate Students Participating in the Dipex Methodology). Flávia Tavares De Souza,Isabela Gaudencio Santos,Arthur Aguiar De Souza,Isabelle Pereira De Oliveira,Joseane Paulino Da Silveira. (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2024.

Covid-APS: experiência dos profissionais da Atenção Primária à Saúde na pandemia. (COVID-APS: Experiences of Primary Health Care Professionals during the Pandemic.) Yago Studart De Lima, Gabriela Paim Vaz, Mayara Barboza Vieira, Nourdine Kanda Moussavou,Fernanda Vaz Branco Becker, Isabelle Pereira De Oliveira, Rayssa Abreu Borges. (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2024.

Metodologia DIPEx (DIPEx Methodology). Arthur Aguiar de Souza, Isabelle Pereira de Oliveira, Joseane Paulino da Silveira, Maria Vitória Tuma de Oliveira, Juliano Luna. (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2024.

Os Desafios que Persistem no Diagnóstico de Hanseníase no Contexto Brasileiro (The Challenges that Persist in the Diagnosis of Leprosy in the Brazilian Context).Isabela Gaudencio Santos, Flávia Tavares De Souza, Júlia Boullosa Souza, Anna Carolina Maurício, Maria Katia de Oliveira. (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2024.

PRESENTATIONS 2025

A experiência de transplantados cardíacos do Nordeste brasileiro: um módulo no Projeto Dipex (The experience of heart transplant recipients in Northeast Brazil: a module in the Dipex Project). Yago Studart de Lima, Gabriela Paim Vaz, Isaac de Farias Cypriano de Souza, Nourdine Kanda Moussavou, Mayara Barboza Vieira, Han-Myo Bayissa, Juliano Luna. (Orientadoras) Alicia Navarro de Souza, Andreza Pereira Rodrigues. SIAC, 2025.

A narrativa de adoecimento como recurso de empoderamento e de construção de pertencimento (The illness narrative as a resource for empowerment and building belonging). Gabriela Paim Vaz,Yago Studart de Lima, Manuela Pimentel Fontes de Azevedo, Gabriela Cali Storry Lins, Thais Viana Neri dos Santos, Mayara Barboza Vieira, Han-Myo Bayissa, Nourdine Kanda Moussavou. (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2025.

Impactos das ações educativas na vida futura-profissional dos Extensionistas Acadêmicos da Dipex (Impacts of educational actions on the future professional lives of Dipex Academic Extension Agents). Mayara Barboza Vieira, Nourdine Kanda Moussavou, Han-Myo Bayissa, Yago Studart de Lima, Gabriela Paim Vaz (Orientadoras) Andreza Pereira Rodrigues, Alicia Navarro de Souza. SIAC, 2025.
https://sistemas2.macae.ufrj.br/siac/cadernoController/gerarCadernoResumo/35000000

Brief Report – XI Ibero-American Congress of Qualitative Health Research (Santiago, Chile, November 4–7, 2025)

The presentation “Voices Without Borders and the Power of International Qualitative Research: Global Lessons from the DIPEx Network During the Pandemic”, by Maria Inês Gandolfo Conceição and Alicia Regina Navarro Dias de Souza, has been accepted for presentation at the XI Ibero-American Congress of Qualitative Health Research (https://ciics2025.cl/), to be held in Santiago, Chile, from November 4 to 7, 2025. During the COVID-19 pandemic, teams from Brazil, the United Kingdom, Spain, Japan, Germany, and the United States collaborated to produce and comparatively analyze more than 300 participant interviews across diverse cultural contexts. The presentation will share cross-national insights on trust in public health guidance, healthcare-seeking strategies, and the intersections of racism and privilege. It underscores the contribution of our collective qualitative work in illuminating the human dimensions of global crises and reinforces the strength of DIPEx’s collaborative and ethically grounded approach to international research.

PUBLICATIONS

Primary Care Health Professionals During Covid-19

Borges RA, Rodrigues AP, Navarro Dias de Souza AR. A experiência dos profissionais de saúde da Atenção Primária na linha de frente durante a pandemia COVID-19: uma revisão narrativa. (The experience of primary care healthcare professionals on the front lines during the COVID-19 pandemic: A narrative review) In: Fonseca Lucas EAJC, Bandeira AMB, organizadores. Multiprofissionalidade e diversidade temática na Atenção Primária à Saúde: revisões bibliográficas como ferramenta para translação do conhecimento. Volume 1. Porto Alegre: Editora Rede Unida; dez. 2024. p. 187-216.
https://editora.redeunida.org.br/wp-content/uploads/2025/03/Livro-Multiprofissionalidade-v1.pdf

Heart Transplantation Experiences
Luna, Juliano Victor. O coração e suas razões: experiência de adoecimento em transplantados. (Heart and its reasons: Illness experience of people undergoing heart transplantation). Tese de Doutorado apresentada ao Programa de Pós-Graduação de Clínica Médica da Universidade Federal do Rio de Janeiro. Orientadores: Antonio José Ledo Alves da Cunha e Alicia Regina Navarro Dias de Souza. março de 2025.

Luna, Juliano Victor, Pinheiro, Marina Assis & Navarro Dias de Souza, Alicia. Illness Experience and Authorship of Life in a “transplanted person” with Lupus: A DIPEx perspective. Lupus 34(4):p 412-414, April 2025. https://doi.org/10.1177/09612033251324498

Pinheiro, Marina Assis; Luna, Juliano Victor & Navarro Dias de Souza, Alicia. Creativity and body: Living metaphors in the context of people undergoing heart transplantation. Integrative Psychological and Behavioral Science 59, 13, January 2025. https://doi.org/10.1007/s12124-024-09879-z

Luna, Juliano Victor; Alves da Cunha, Antônio Ledo; Navarro Dias de Souza, Alícia. Illness Experience in Heart Transplant Patients: A Narrative Review. JRG Estudos Acadêmicos Brasil, São Paulo, v. 7, n. 15, p. e151602, 2024. https://doi.org/10.55892/jrg.v7i15.1602

Luna, Juliano Victor; Oliveira, Maria Vitoria T.; Castellanos, Marcelo; Conceição, Maria Inês G.; Rodrigues, Andreza P.; Navarro de Souza, Alicia; Alves da Cunha, Antonio José L.: (2026). DIPEx Brazil: Innovative Solution in Digital Health and Education in a Multicultural and Diverse Country. In: Pereira, L., Krus, P., Klofsten, M. (eds) Beyond Boundaries: Unleashing Innovation with Ideas. Proceedings of IDEAS 2024. Design Science and Innovation. Springer, Cham. Published online 01 October 2025 https://doi.org/10.1007/978-3-031-96173-1_28

Health Experiences Research Canada

By Susan Law

NEW MODULES ONLINE

Experiences of Long COVID. Funded by the Canadian Institutes of Health Research (CIHR).
See: https://healthexperiences.ca/long-covid/

From the heart: women's experiences of heart failure. Funded by CIHR.
See: https://healthexperiences.ca/heart-failure/

Mental health and pregnancy. Funded in part by the Royal Bank of Canada Foundation.
See:
https://healthexperiences.ca/perinatal-mental-health/

We are continuing to promote these modules through direct communications with relevant national and local organizations, healthcare professional groups and social media.

STUDENTS & TRAINEES:

We have welcomed several students (current and future) and trainees who have contributed to our research program. The first two are leading new modules with HERC!

Asha Ulusow is a Research Coordinator at Women's College Hospital in Toronto and a prospective MSc student at the University of Toronto. Asha holds two grants already (based at Women's College Hospital under mentorship of Dr. Mona Loutfy), entitled Harnessing Opportunities for Progress Through Patient Experience (HOPE) from the Ontario HIV Treatment Network (OHTN). She is leading, with supervision and support from HERC, a study investigating the experiences of young people living with HIV.

Savannah Dubé, PhD student (co-supervised by Susan with Dr. Katie Dainty) at the School of Behavioural Health Sciences, University of Toronto. She will lead a module exploring the lived experiences of people with premenstrual dysphoric disorder in Canada, including the development of strategies for improved care. She is the recipient of three (!!) doctoral awards from CIHR, the Quebec-based FRQS, and Desjardins (financial institution in Canada).

In 2024/2025, Emilie Richer joined us for a practicum placement; she was an undergraduate health sciences student at University of Western, Ontario, now starting her Master's degree in health sciences and nutrition at McMaster University. Emilie provided support for our knowledge mobilization strategy for our new HERC modules.

Susan continues to be a mentor for an American high school student Caitlyn Lupia, enrolled in a high school research program. Caitlyn and her school supervisor found us through one of our perinatal mental health publications! She is focusing on perceptions and experiences of stigma in a secondary analysis of selected perinatal mental health transcripts from the HERC module.

Susan is also an advisor for a University of Toronto medical student Jazlyn McGuinty who is working on a secondary analysis of women's experiences of heart failure data to explore intersectional aspects of younger women's experiences of heart failure.

In May 2025, we enjoyed helping to host University of Oxford DPhil student Bakita Kasadha as a University of Toronto visiting student at the Social and Behavioural Health Sciences Division of the Dalla Lana School of Public Health.

PROPOSALS SUBMITTED FOR FUNDING

- CIHR Project Grant (Fall 2025). Learning from diverse peoples living with multiple sclerosis experiencing invisible symptoms in Canada. $555,000 (3 years). Submitted October 2025. Notice of decision January 2026.
- CIHR Project Grant (Fall 2025). Integrating personalized risk visualization to influence health beliefs and self-management behavioural intentions in young-onset Type 2 Diabetes. $870,000 (4 years). Submitted September 10, 2025. Notice of decision January 2026.
- CIHR Catalyst Grant – Partnering for Impact (Fall 2025) Designing a new community-based program for health and social care. Listening for direction from asylum seekers in Canada. Amount requested: $124,607 (1 year). Submitted October 23, 2025. Results announced February 24, 2026.
- SSHRC Insight Grant (Fall 2025). Beyond the Individual: Understanding Systemic Drivers and Social Ecologies of Burnout among Diverse Canadian Health and Social Care Workers. $375,000 (3 years). Submitted September 2025. Notice of decision April 2026.
- MS Canada Discovery Grant (Fall 2025). Learning from diverse peoples living with multiple sclerosis experiencing invisible symptoms in Canada. $296,872 (2 years). Submitted October 4th, 2025. Notice of decision March 2026.

RECYCLING DEPARTMENT!

As always, we have grants that didn't make it through so will be looking to recycle the hard work in future grant applications – on chronic pain and women military veterans, gynaecological cancers, Ukraine refugee experiences of transition and health, and young people and death literacy.

OTHER ACTIVITIES

- Our Japanese colleagues at DIPEx Japan asked if our Canadian team would permit the translation of our family caregiving module from English to Japanese. We are delighted that this content could be useful to others around the globe! Yes!!
- Since January 2025, a team comprised of six HEXI countries have been working together to apply to the JTC-THCS 2025 Call. An innovative, qualitative and arts-based approach was proposed to explore the impact of homecare policies on aging adults and their informal carers. Our team just recently learned that we have not been funded. We do hope, however, that our ongoing conversation over the past year will motivate us to keep working together and find another funding opportunity.
- Following the HEXI meeting in Norway, members of the Canadian and the US teams (HERC and HERN) have been meeting monthly to discuss a potential collaboration around lived experience of multiple sclerosis (MS), invisible symptoms and intersectionality. We hope to build from the US experience and recently published module on MS to develop a joint project.

WEB UPDATE

Our healthexperiences.ca website has had 140,443 users so far, with a total of 314,618 views across all webpages, 73% of web traffic originating through Google, with the website accessed globally, with each user viewing 2-3 pages per visit, and visits lasting 2-8+ minutes. Our web modules to date include breast cancer, family caregiving, Long COVID, heart failure in women, perinatal mental health, and patient-researcher partnerships, with additional projects, including catalyst films, posted on immigrant mental health and living with an amputation.
With thanks to Ryan Caulfeild and Yousra Lakhani for their support on these activities.

HEXI INTERNATIONAL COLLABORATORS' MEETING:

June 2-6, 2025. Trømso and Sommarøy, Norway

Susan, Émilie and Fred were thrilled to attend the 2025 in-person collaborators' meeting held in northern Norway. Susan presented with Hege Andreasson on the Ukrainian refugee project and Émilie presented on the international research proposal (PI: Vinita Mahtani) submitted on enhancing community and primary care to the 2025 call from the EU Joint Transnational Call Better Care Closer to Home. We invited some Canadian colleagues working in Indigenous health research to participate in the open conference held on June 2nd in Trømso on Indigenous health: Rani Sanderson, Director of StoryCentre Canada; Bobby Henry, Canada Research Chair in Indigenous Justice and Well-being, University of Saskatchewan; and, Chelsea Gabel, Scientific Director of the CIHR Institute of Indigenous Peoples' Health, and Associate Professor at McMaster University. We look forward to attending the next virtual collaborators' meeting in 2026, and in-person meeting in Berlin, Germany.

HERC TEAM NEWS

The Health Experiences Research Canada Team has grown!

We have been delighted to welcome several new members to our national network. Dr. Terence Tang, General Internal Medicine physician at Trillium Health Partners has accepted the position of HERC Medical Advisor. He is also a clinician scientist with research interests in health informatics, user-centred system design and co-design, implementation and evaluation, as well as care transitions, interprofessional collaboration, AI, and compassion. We now have lead roles within our network for the Atlantic region (Dr. Emily Gard Marshall, Dalhousie University), Western region (Dr. Maria Santana, University of Calgary), and for Indigenous Health (Dr. Rheanna Robinson, University of Northen British Columbia). Dr. Robert Simpson, rehabilitation physician and clinician researcher at University Health Network and University of Toronto, has led several grant applications over the past two years with HERC for modules related to experiences of 'invisible symptoms' in multiple sclerosis and healthcare professional burnout. These individuals bring excellent track records in their own research areas, scientific leadership, and a passion for the power of personal narratives, as well as fresh ideas and terrific networks of their own that will help to expand our reach, including professional and patient connections.

CONFERENCE PRESENTATIONS

- Law S, Gould G, Krowlikowski K, Senese D, Graves L, Riley J, Macarthur C. Learning for learning health systems: an environmental scan of training opportunities in Ontario, Canada. International Conference on Integrated Care, April 13-15, 2026, Birmingham UK. Submitted as oral presentation October 17th, 2025. Notice of decision December 20th, 2025.
- Whitney C, Grob R, Mahtani-Chugani V, Dixon S, Law S. Beyond "Passing the Tissue Box": Navigating the ethical landscape of "empathetic load" in qualitative research through compassionate action. Submitted to the 2026 World Congress of Bioethics, July 8-10th, 2026, Johannesburg, South Africa.
- McGuinty J, Mansfield E, Tang T, Law S. Understanding the lived experiences of young women with heart failure in the Canadian healthcare system. CSIM/ACP Atlantic Provinces Chapter 2025 Meeting, October 15-17, Halifax, Nova Scotia. Poster presentation.
- Law S, Ormel I, Lypovsky A, Montanez J, Southall K, Makarenko D, Naumova D, Smith L. Learning from the experiences of Ukraine refugees in Canada – an initiative to train qualitative researchers and conduct pilot interviews with refugees in Canada. Oral presentation at the North American Refugee Health Conference (NARHC), Niagara Falls, ON. September 11-13, 2025.

- Law S, Dionne E. Engaging arts students Oral presentation at 2024 Virtual DIPEx International Collaborators' Meeting. November 26, 2024.
- Law S, Smith L, Breuning M. DI International Collaborations – Medical Cannabis and Chronic Pain. Oral presentation at 2024 Virtual DIPEx International Collaborators' Meeting. November 26, 2024.
- Lannon H, Sandercock J, Marcinow M, Nie J, Law S. From the heart: Canadian women's experiences of heart failure. Poster presented at the 2024 Canadian Cardiovascular Congress, Vancouver BC. October 2024.
- Macarthur C, Law S, Graves L, Krolikowski K, Gould G, Senese D, Riley J. Learning for Learning Health Systems. Oral presentation to the OSSU Learning Health System Working Group. October 11, 2024.
- Law S, Rozmovits L, Marcinow M, Ormel I, Reid R, Hayes A, Pindera L, Gutnick D, Patino A, Curran J, Tang T, Mansfield E, Kuluski K, Marwaha S, Dionne E. Living with Long COVID. Learning from lived experiences to inform patients, policy and practice. Poster presented at the 2024 Long COVID Web Symposium, Edmonton AB, October 1-4, 2024.
- Christopoulos T, Décary S, Senese D, Krolikoswki K, Gould GK, Giannarakos A, Law S. What has been the health system response to organize care delivery for people living with Long COVID/Post-COVID Condition (PCC)? A scoping review. Poster presented at the 2024 Long COVID Web Symposium, Edmonton AB, October 1-4, 2024.
- Macarthur C, Law S, Graves L, Krolikowski K, Gould G, Senese D, Riley J. Learning for Learning Health Systems. Oral presentation to the OSSU Training and Capacity Development Working Group. July 15, 2024.
- Nunes da Silva J, MacDonald S, Law S, Gopaul U, Bayley M, Munce S. Influences of sex and gender-related variables on willingness to participate in stroke research studies. Poster presentation at the Rehabilitation Sciences Institute's Research Day. Toronto, Ontario, Canada. May 30, 2024. Award: Research Excellence Award from Rehabilitation Sciences Institute – related to the project as a whole and what Juliana has achieved with it.

PUBLICATIONS 2024/2025

- Minogue V, Vicary P, Law S. Chapter 2: Bridging the gap: moral and ethical issues within Patient and Public Involvement in research – tensions and dilemmas. In: John Salsberg and Virginia Minogue (Editors), Meaningful and Safe: The ethics and ethical implications of patient and public involvement in health and medical research. Ethics International Press, UK. September 20, 2024. Print Book ISBN: 978-1-80441-545-0; eBook ISBN: 978-1-80441-546-7. https://ethicspress.com/products/meaningful-and-safe?INTEGRITY
- Rennick J, Southall K, Carnevale F, Dryden-Palmer K, Patel H, Dagenais M, Buchanan F, Avery S, Razack S, St-Saveur I, Cohen E, Fontela P, Law S. Exploring care experiences and identifying practice change priorities to enhance pediatric intensive care for children with medical complexity using Experience-Based Co-Design. BMJ Open 2025, 15(5): e096181. https://bmjopen.bmj.com/content/15/5/e096181.full or https://doi.org/10.1136/bmjopen-2024-096181
- Montanez J, Kairy D, Gilbert M, Gulino N, Ormel I, Pytka-Jones R, & Law S. (2025). "I would not want my leg back": Living experiences of adult amputees following intensive functional rehabilitation. Rehabilitation Psychology. Advance online publication. https://doi.org/10.1037/rep0000617
- Hoosein S, Winchester P, Babinski S, Smith N, Bahvsar P, Law S. An exploratory qualitative study of perinatal experiences in an acute setting during early phases of the COVID-19 pandemic. Patient Experience Journal 2024; 11(3): 85-96. https://doi.org/10.35680/2372-0247.1896.

- Hoosein S, Winchester P, Babinski S, Smith N, Bahvsar P, Law S. An exploratory qualitative study of perinatal experiences in an acute setting during early phases of the COVID-19 pandemic. Patient Experience Journal 2024; 11(3): 85-96. https://doi.org/10.35680/2372-0247.1896.

CZECH REPUBLIC

By Veronika Navratilova

Expansion of existing HEXI module
Since our last update, we have been able to expand the Mental Health in Children module with a new section in which experts (psychologists and psychiatrists) offer their professional recommendations related to the case studies. We hope these reflections will provide inspiration and practical insight for parents, teachers, and mental health professionals working with this topic.

New HEXI module in development
Since autumn 2025, we have had the honour of beginning intensive work on a new module focusing on Posterior Fossa Tumors in Children. On this project, we are collaborating with the Department of Neurosurgery for Children and Adults of the Second Faculty of Medicine, Charles University and Motol University Hospital. This institution is the spot in which the vast majority of such tumours are surgically treated in paediatric patients in the Czech Republic.
Malignant posterior fossa tumours are among the most common childhood brain cancers. Despite steadily improving survival rates, they often carry long-term neurological, neurocognitive, and psychosocial consequences. Long-term follow-up studies describe highly variable quality of life outcomes: while some survivors function comparably to the general population, a significant proportion continue to experience ongoing difficulties. These challenges may affect school achievement, relationships, social participation, and the overall wellbeing of the child and their family.
To date, the Czech Republic lacks an in-depth qualitative understanding of the lived experiences of children, their families, and professionals throughout treatment and follow-up care. The new module on “Hovory o zdraví” thus has the potential to become a valuable source of information, support, and understanding.

Expansion of the Czech HEXI team
In connection with this new project, we are delighted to share another piece of good news: our team has grown. Doctoral candidate Tereza Smith has joined the Olomouc University Social Health Institute and will be responsible for developing the new module described above. She will work under the supervision of Kristýna Gábová and with the support of Veronika Navrátilová and Peter Tavel.

Publications
During the period covered by this newsletter, the Czech team published several studies based on data collected and analysed using the DIPEx/HEXI methodology:

GABOVA, K., BEDNARIKOVA, H., MEIER, Z., & TAVEL, P. (2024). Exploring intimacy and family planning in Inflammatory Bowel Diseases: a qualitative study. Annals of Medicine, 56(1), 2401610.

GABOVA, K., MEIER, Z., & TAVEL, P. (2024). Parents’ experiences of remote microphone systems for children with hearing loss. Disability and Rehabilitation: Assistive Technology, 19(3), 831-840.

BEDNARIKOVA, H., GABOVA, K., ZELINKOVA, Z., MEIER, Z., & TAVEL, P. (2024). Inflammatory bowel disease patients’ expectations of care: insights from a qualitative study. European Journal of Inflammation, 22, 1721727X241281504.

Conference contributions
Members of our team and close collaborators also had the opportunity to present conference papers showcasing our modules and related research:

SANDORA, J., ČERNÍKOVÁ, K., KLŮZOVÁ KRAČMÁROVÁ, L., TRTÍLKOVÁ, J., GÁBOVÁ, K., MEIER, Z., TAVEL, P. Family in the face of childhood epilepsy: a parental perspective – a qualitative study.

38th Annual Conference of the European Health Psychology Society. 3–6 September 2024, Cascais, Portugal.

SANDORA, J., BEDNAŘÍKOVÁ, H., GÁBOVÁ, K., MEIER, Z., TAVEL, P. “We want to hear your story”: How patients respond to an IBD diagnosis. New Horizons in Qualitative Research. 5–6 February 2024, Bratislava, Slovakia.

BEDNAŘÍKOVÁ, H., & GÁBOVÁ, K. Presentation of the “Talking About Health–Inflammatory Bowel Disease” module for patients with IBD in the Czech Republic. 2nd Slovak Gastroenterology Congress, 6–7 December 2024, Košice, Slovakia.

NAVRÁTILOVÁ, V. Lyme Disease. DIPEx International Meeting, 3–6 June 2025, Norway.

Project application

In 2025, we were also honoured to take part in the preparation of a joint international project submitted under the call “Transforming Health and Care Systems – Joint Transnational Call 2025 – Better care closer to home: Enhancing primary and community care.” This collaboration focused on the experiences of older adults navigating the boundary between home-based and institutional care and involved partners from Spain, Canada, Norway, the Netherlands, and Switzerland, under the exceptionally effective and kind leadership of Vinita Mahtani Chugani. We were also very pleased to get to know the wonderful Emilia Dionne, who, together with Vinita, was a driving force behind the project concept. Although the proposal was not ultimately funded, we appreciate reaching the final selection round and receiving several highly positive reviews from evaluators. We hope that we will succeed together in similar international collaborations in the future.

In-person meeting

Finally, we would like to express our sincere thanks to the organizers of the wonderful June 2025 meeting in Tromsø/Sommarøy, Norway. For those of us who were able to attend, it was a true pleasure to meet colleagues from other HEXI/DIPEx teams in person. The event provided not only fresh motivation for our work but also a strong sense of joy and appreciation for the research community we share—one that is professional, supportive, and genuinely friendly.

Germany

By Anne Kathrin Thier

The team of DIPEx Germany consists of Christine Holmberg (project manager), Martina Breuning (scientific supervision), Lisa Korte (researcher), Helen Frenzel until September 2024 (research assistant), , Anne Weber (student) and Inga Geiermann (student); Cynthia Huynh (research intern wintersemester 2024/25) and Anne Thier (coordination).

WEBSITE
The interview phase for the skin cancer module has been completed, with a total of 41 interviews conducted. The project team is now developing the module, which is scheduled to go online in Spring 2025, making these experiences accessible for patients, caregivers, and healthcare professionals. As part of identifying interview participants, Lisa attended the Self-Help Action Day in Potsdam, engaging with patients and raising awareness about the project.

Figure 1 Lisa at the Self-Help action day in Potsdam

The new Post-COVID module, along with the updated COVID-19 module, was publicly launched during a symposium at the Medical School Brandenburg Theodor Fontane in Brandenburg an der Havel (funding from the federal institute of public health). The symposium highlighted that Long-/Post-COVID is a complex, chronic condition with often unclear causes, underlining the urgent need for causal therapy studies and specialized, coordinated care. It emphasized that patients should be recognized as experts in their own experiences, as their stories provide essential insights for empathetic and informed care. Access to reliable information, professional networking, and supportive resources is crucial to improve outcomes and sustainably support those affected.

The updated COVID-19 module, now featuring 66 narratives, shows how this previously unfamiliar illness, initially associated with great fear, is gradually becoming better understood and normalized as more people have experienced it. The Long-COVID module features a total of 42 personal narratives, highlighting the wide range of experiences among affected individuals. Stories cover periods of exhaustion lasting from weeks to years and reflect experiences from self-help strategies to navigating medical uncertainty.

The modules for breast, colon, and prostate cancer on krankheitserfahrungen.de, originally published in 2012/2013, have been updated in April 2024with new personal stories thanks to funding from the Krebsallianz. Currently, the platform features stories from 50 breast cancer patients, 47 colon cancer patients, and 49 prostate cancer patients, providing a rich insight into life with cancer. During the update, the perspectives of young people with breast and colorectal cancer were expanded, with greater emphasis on topics such as family planning and fertility. Additionally, many contents were revised to be more diversity-sensitive. New care options, psycho-oncology, self-help, and prevention were highlighted more strongly, while holistic care has become increasingly nuanced and acknowledged among those affected.

WORKSHOP

In May 2024, the WeCareForCancerCare project at the Medical School Brandenburg Theodor Fontane (MHB) held its first workshop focusing on men with breast cancer. The event drew on findings from “krankheitserfahrungen.de”, providing a scientific foundation to develop practical recommendations for better patient care. The event brought together male patients to share their experiences navigating a disease often perceived as a “women’s illness.” Female breast cancer patients and health professionals also shared their experiences. Participants discussed challenges such as delayed diagnoses, unclear care pathways, limited awareness among healthcare providers, and gaps in follow-up and rehabilitation services. The workshop highlighted the importance of patient-centered approaches and the need for clear guidance, specialized care, and resources tailored to men. Attendees emphasized that sharing personal experiences can support other patients, improve healthcare provision, and inform future research.

CONFERENCE Highlights

- Breast, Colon, and Prostate Cancer Experiences: Presentation and poster at BKVF 2024 (Brandenburg Congress for Health Services Research) and the 8th HAM-NET Symposium 2025 (Hamburg Network for Health Services Research) in Hamburg on “Dealing with and talking about oneself after a cancer diagnosis – reflection patterns of people with breast, colon, and prostate cancer.”
- Skin Cancer Experiences: Posters at the DGSMP 2025 Annual Conference (German Society for Social Medicine and Prevention) on “Resources in the context of participation and empowerment of people with skin cancer” and at the EPH Conference on “Psychosocial burden and coping among individuals with skin cancer: Insights from a qualitative study.”
- COVID-19 / Long-/Post-COVID Experiences: Presentation at DGSMP 2025 on “Patients as co-producers of knowledge in healthcare.”

Japan

By Hikaru Mizuno

Illness/Disability × Disasters — learning with our existing modules
Japan's 2024 began with the Noto Peninsula earthquake and, later, severe autumn flooding—fresh reminders that our country ranks among the world's most climate-risk-exposed nations (4th in 2019; 1st in 2018 on the Global Climate Risk Index). Against this backdrop, DIPEx-Japan convened an online symposium, "How can we prepare for disasters with illness and disability—thinking together from lived experience," held as a Zoom webinar on July 6, 2024. Program and recordings: https://www.dipex-j.org/news/2024symposium-video/

The symposium opened with audio-visual testimonies from two existing DIPEx-Japan modules—"Families of Children Requiring long-term Medical Care" and "Dementia". From "Families of Children Requiring Medical Care," we highlighted disaster-related stories that emphasized both "things" (power for life-sustaining devices; stocks of essential supplies) and "people" (joining drills; building understanding with neighbors in advance). From "Dementia," we watched the three-part video series "Let's think about building towns that can protect people with dementia from disasters"—on blackouts, confusion around evacuation orders, and a group-home evacuation during torrential rain. These materials make visible why some hesitate to evacuate—reluctance to "be a burden," uncertainty about shelter reception—and point to practical, community-anchored ways to act earlier and more confidently. Module links: https://www.dipex-j.org/med-care-child/topic/care/disaster ; https://www.dipex-j.org/news/katariba_video/ .

Speakers included a representative of the IBD Network (a nationwide patient association for inflammatory bowel disease), a parent of a child requiring medical care, a disability self-advocate from a Center for Independent Living, and a university-based disaster-risk-reduction researcher (moderator). The IBD Network described a pivot to "readiness in ordinary times," using group work to draft plans for wind/flood, earthquakes, tsunamis, and shelter life—preparing two-week reserves of water, medications, and stoma/toilet kits. The parent outlined home resilience—solar and storage batteries, a dual-fuel generator—and advocacy for subsidies covering solar panels and storage batteries. Disability advocate linked daily independence to survival, removing wheelchair barriers and promoting individualized disaster plans. In the panel discussion, speakers drew on their own experiences to discuss disaster-time challenges and solutions with communities. Preparedness grows from lived stories, neighbor ties, and collaboration with schools and municipalities.

Narratives of Natural Stillbirth — why we are starting this now

In April 2024, DIPEx-Japan launched the "Narratives of Natural Stillbirth" project. The decision has a long backstory. Twenty years ago, when support after discharge was scarce, monthly in-person talking circles began for parents who had lost a baby. Midwives and graduate students helped host; five to eight people sat together and said the things that could not easily be said elsewhere: "It's been three months and I still can't go out," "I cry all day while my partner goes to work," "I don't know how to tell friends or colleagues." The circles made visible what textbooks missed — grief alongside very practical questions.

Listening to parents' stories changed the practice. Families described an "invisible loss": others could not see what had happened, yet the parents could not forget. They asked for small, human gestures—meeting and holding the baby, taking photographs, making a keepsake—acts that acknowledged a life and steadied the days that followed. Over the years, education in Japan began to include perinatal loss more clearly, and evidence-based midwifery guidance shifted to encourage, when parents wish, contact with the baby, photos, and mementos. At the same time, many parents still faced uncertainty—causes often remain unknown even after extensive tests—and searched for orientation about remembrance, returning to daily life, and thinking about a future pregnancy.

This is the path that brings us to the present. After two decades of listening in community settings, we have begun a DIPEx module to reflect these experiences in parents' own words. That is why, in April 2024, we started this project. This project is currently in progress.

Educational Utilization Working Group — our blog

DIPEx-Japan has an Educational Utilization Working Group whose core mission is to bring DIPEx narratives into healthcare education for students, trainees, and practicing professionals. To share this work more widely—and to make the database easier to navigate from an educational angle—we launched a public blog.

The blog helps educators and trainees find what they need quickly, with concise signposts organized by education-facing keywords and tags. Each entry names a teaching focus (e.g., communication with healthcare professionals), offers a brief note on why the story matters for learning, and links directly to the relevant narratives. Visitors can browse by skills or scenarios—such as shared decision-making, family caregiving, or transitions between services—and then adapt the linked stories for their own context.
URL: https://dipex-japan-education.blogspot.com

Summer Retreat

In August 2025, DIPEx-Japan held a two-day summer retreat in Tokyo. Members gathered to connect with one another and discuss the organization's future direction. For many who usually meet online, the retreat offered valuable in-person time to deepen relationships and plan next steps.
Reception at the DIPEx-Japan summer retreat, Tokyo (August 2025)

Publications

Hamashima Y, Sakamaki K, Hamashima C. Participants' and non-participants' views of workplace-based colorectal cancer screening in Japan: a secondary qualitative study. BMC Public Health. 2025 Sep 24;25:3099. doi: 10.1186/s12889-025-23827-5.
https://pmc.ncbi.nlm.nih.gov/articles/PMC12462325/

Netherlands

By Manna Alma

New team members
In the last year, we have had the pleasure of welcoming two new members to the Dutch HEXI team. First, Alina Rozeboom, whom many of you have already met in Norway. Alina was previously involved in the development of the Post-Covid module. Now, she assumes a more formal role within the Dutch HEXI team. She is responsible for coordinating the website and other HEXI related activities. Furthermore, together with Andrea, she is actively engaged in acquiring funding for new modules.
We have also welcomed Annemarie de Jong-Bardelmeijer to our team. Annemarie is a PhD student at the University Medical Center Groningen affiliated with the department of primary care – midwifery science. She has a background as a midwife. Under the supervision of Manna, she is working on the module concerning postpartum experiences (see below).

New project: Postpartum module.
This project aims to gain a deeper understanding of the experiences of women during the first year after childbirth, focusing on their health, access to healthcare, and the transition into motherhood. It is a collaboration between the Dutch HEXI team and the Childbirth Network of Midwifery Science, based in Amsterdam and Groningen, the Netherlands. The project team consists of Manna Alma, Annemarie de Jong-Bardelmeijer, and Esther Feijen-De Jong.
We started conducting interviews in April 2025. By October 2025, 27 interviews had been conducted, marking the final phase of the inclusion period. At this stage, the project is including the final participants to achieve maximum variation within the participant group. We have succeeded in including a diverse range of participants in terms of ethnic background, disabilities, and vulnerabilities. The interviews also reflect a wide variety of experiences related to physical and mental health challenges, postpartum recovery, impact on relationships, and social support networks. The launch date for the module has not yet been determined but is expected to be in the summer or autumn of 2026.

Update project: experiences of menstruation
This project aims to better understand the personal experiences of menstruation and related complaints and is a collaboration between the HEXI team and the Máxima Medical Centre. Lisa and Manna from the Dutch HEXIx team are involved and Jaklien Leemans, Peggy Geomini and Marlies Bongers from the Maxima Medical Centre. The project is funded by Fonds Alledaagse Ziekten (Fund Everyday Illnesses) and co-funded by the Innovation Fund of Máxima Medical Centre.
In January 2025 we launched the module: a collection of 33 personal stories with experiences from varying diagnoses, from varying ethnic and cultural backgrounds and two transmen. The launch was celebrated with a successful event and received media attention, underlining the relevance of the topic. Since then, the project has sparked ongoing dialogue through invited talks. For example, Manna and Lisa were invited to the Noorderzon Festival of Performing Arts, where they gave a talk on menstrual narratives and engaged a broad audience in reflecting on taboos and social norms. Lisa is currently working on secondary analysis for articles for her PhD dissertation.

Figure: Lisa at the launch of the module on menstruation

Figure: Manna and Lisa at Noorderzon Festival of Performing Arts

Update: Project Psychosis

Last Spring we officially launched the 'Psychotic susceptibility' module on the Dutch Hexi website 'PratenOverGezondheid.nl'. The final module is a collection of 24 participants' stories. The themes range from topics such as stigma to the importance of leisure time and present how widely diverse psychosis susceptibility is experienced and lived.

Because it is important to include the different experiences of psychosis susceptibility, we have also included experiences from 20 persons who are in FACT-teams (Flexible Assertive Community Treatment), long term clinical care and/or (independent) protected living. Since we were asked to keep these stories anonymous and intractable to the real participants, we have worked together with an inclusive theatre company 'Theatre Babel' based in Rotterdam to use these experiences as input for written monologues that give an impression of their daily life. The monologues were performed and filmed and have a dedicated place in the module, so they are not mixed up with the rest of the module.

Finally, we used the input from the project to create trigger films that can be used as tools for education and the 'Ask us' methodology, a co-creational methodology created by Marjolijn Heerings to start conversations about challenges, feelings and experiences in healthcare organisations.
To mark the launch, we created an animation about the method, a short clip about the specific module, and a flyer. All these materials were sent to various stakeholders and mental health care organizations.

Visit from HEXI team Slovakia

Following the successful visits by the Slovak team in 2024, we were pleased to welcome them again this year. Once more, we exchanged experiences, including those related to the development of website modules, communication and dissemination strategies, as well as writing publications and engaging in educational activities. We also made plans to further strengthen the collaboration between both countries.
It is highly likely that we will initiate a double PhD programme with Lubica Pamulova, under the supervision of Zuzana and Andrea (from Slovakia), and Manna and Menno Reijneveld (from the Netherlands). This initiative is part of a broader, long-term collaboration between the universities of Košice and Groningen. For the first time, a HEXI PhD student will be included in this partnership. Lubica has already submitted her first article, based on Slovak HEXI data.

PR activities

In collaboration with Klare Koek, a communications agency, we developed an animation that clearly conveys the importance of our methodology and website in just one minute. This animation is available on our website, is used in presentations, and can be shown in general practitioners' waiting rooms. You can find the animation at our homepage https://www.pratenovergezondheid.nl.

At the end of September, the European Researchers' Night took place. As part of this event, a science festival was organized in Groningen, where we hosted a stand to promote our website. We engaged visitors in conversations about discussing health. Furthermore, visitors were also invited to vote on the topic of our next module. Most votes were cast in favour of a new module on menopause or mental health.

Figure: European Researchers' Night at the Forum in Groningen

New plans / submitted

Finally, we are currently working on plans for new modules. For instance, we are participating in the HEXI proposal led by Vinita and Emily. In addition, we are developing plans for modules on chronic pain, mental health among young people, menopause, and the experiences of relatives of individuals with intellectual disabilities. For the latter two modules, several sociology students will start conducting interviews early next year.

We look back on a very successful and inspiring meeting in Norway. And we hope to see you all soon!

Greetings from Manna, Roman, Andrea, Alina, Lisa, Annemarie, Joyce, Marjolijn

Figure: The Dutch HEXI team in Norway

Figure: Diner in Tromso

Relevant HEXI related papers

Zuidema, L., van Luik, E. M., Alma, M. A., Leemans, J. C., Bongers, M. Y., & Geomini, P. M. A. J. (2025). Informational needs related to menstrual literacy among Dutch women: a focus group study. BMC Women's Health, 25, Article 158. https://doi.org/10.1186/s12905-025-03694-3

Norway

By Hege Kristin Andreassen

The Norwegian group had the pleasure of hosting the 2025 DIPEx meeting, gathering 75 colleagues from around the world for an inspirational week at beautiful Sommarøy in North Norway. The meeting sparked our motivation with days filled of collegial dialogue, beautiful walks and boat trips, high quality presentations and in depth discussions on the methods and visions of our research in a new era where technological innovation increasingly touches upon our professional practice as researchers and disseminators of knowledge.

Slovakia

By Lucia Bosakova

Current Projects

This year has been an exceptional one for our team, filled with progress and development across all our research modules. Our three ongoing projects — Children in the System of Care (led by Zuzana Dankulincová), Parents of Children in the System of Care (led by Lucia Bosáková), and Narcolepsy (led by Ján Hlodák) — are all actively moving forward in their OSOP preparation phase. The module focusing on dialyzed patients with kidney diseases, previously led by Ivana Skoumalová, has seen a leadership change. Since November, Ján Hlodák has taken the lead, and the project is now in the process of transcribing the interviews conducted jointly by Ivana and Ján. Altogether, our four modules are developing steadily and showing great momentum. In addition, during the second half of the year, we officially launched a new project led by our colleagues at Comenius University in Bratislava, exploring experiences with childbirth (led by Katarína Greškovičová).

DI Online Meetings

Throughout 2024, we took part in several DI online meetings with the broader DIPEx community. Even though the sessions took place late at night for our team, they were full of inspiration, updates, and lively discussions. We were also happy to contribute to the program! Zuzana co-presented with Manna Alma about our training experience in the Netherlands, sharing what the process was like and what we learned. Later, Ján gave a presentation on how we use DIPEx modules in teaching in Košice and Bratislava, as well as how these modules can be adapted for training secondary nursing students.

Conference symposium

In February 2024, the DIPEx Slovakia research team presented the DIPEx methodological approach and several ongoing module projects at the New Horizons in Qualitative Research conference in Bratislava. The session, opened by Zuzana Dankulincová, introduced the DIPEx methodology and highlighted insights from young people and their parents navigating the Slovak system of care. Ivana Skoumalová then presented the module on chronic kidney disease and dialysis, emphasizing patients' lived experiences beyond clinical outcomes. Ján Hlodák followed with a presentation on narcolepsy, discussing the challenges faced by individuals living with this rare neurological condition. The presentations sparked strong interest among participants and highlighted the relevance of qualitative research in health. The event also opened new opportunities for collaboration with Comenius University in Bratislava and for expanding DIPEx Slovakia's research portfolio.

New Team Members
Our Slovak DIPEx team continues to grow! This year, we've strengthened collaboration between Pavol Jozef Šafárik University in Košice and Comenius University in Bratislava. The new team at Comenius University began its training in Košice and has established an advisory board for its first project, BIRTH – Experiences with Labour. We're delighted to see this new collaboration connecting the eastern and western regions of Slovakia. It's an exciting opportunity to expand our research and add a meaningful new topic to our portfolio.

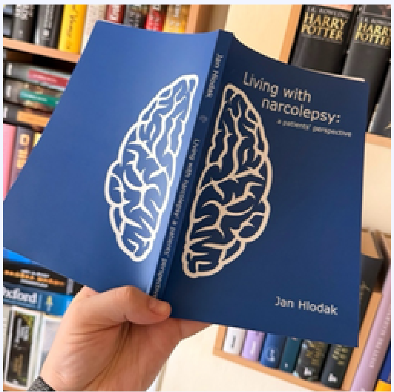
New PhD Student
Since September 2024, we've welcomed a new PhD student, Ľubica Pamulová, supervised by Zuzana Dankulincová. Before starting her PhD, Ľubica worked as a school psychologist, and she has now joined the project exploring young people's experiences with the system of psychological and psychiatric care. She and Zuzana are currently working on analysing interviews and preparing their first OSOPs. We're very happy to have Ľubica on the board and look forward to seeing her research journey unfold.

Finishing the Interviews
We're excited to share that we've completed all interviews for our current projects! The final interview for the Narcolepsy module took place in August, conducted by Ján. This project now includes a total of 25 participants living with this rare sleep disorder, and their interviews are currently being analysed. In October, Ján and our new PhD student Ľubica travelled to eastern Slovakia to carry out the last four interviews with dialyzed patients. It was Ľubica's first experience as a co-interviewer — an exciting milestone for her and a valuable step in her research training.

Current Projects
This year has been a period of great progress for the Slovak HEXi team. Our projects have continued to move forward, and several important milestones have been achieved. The modules focusing on young people and their parents' experiences with the system of care and narcolepsy have advanced to the OSOP stage, and work has begun on preparing materials for the Slovak HEXi webpage. The dialysis module is currently in the data analysis phase, and the team is preparing the first article based on these findings. Meanwhile, the birth experiences module, led by our colleagues in Bratislava, is actively collecting interviews.

Training in Groningen
In January 2024 and January 2025, our Slovak team visited the Dutch team in the Netherlands for a special training session led by Manna Alma in Groningen. The training focused on initial coding, developing coding structures, creating OSOPs, and writing topic summaries. The second training focused primarily on webpage development. These sessions gave us a deeper understanding of the steps that follow interview transcription and taught us valuable skills for the analysis phase. It was also a great opportunity to reconnect with our international colleagues, strengthen our partnerships, and exchange ideas for future research and educational collaborations.

First HEXi Slovakia Publication and Successful PhD Defences
In July 2025, the Slovak HEXi team reached an important milestone with the publication of its first paper using HEXi methods. The study explored how patients with narcolepsy perceive and experience their symptoms and examined the burden these symptoms create in their everyday lives. We are also delighted to share that our colleague Ján Hlodák has successfully completed and defended his doctoral thesis, titled "Living with Narcolepsy: A Patients' Perspective." He received his PhD in Health Psychology. We are especially proud that Professor Lorraine Smith from the Australian HEXi team served as one of the thesis reviewers and opponents.



DI Meeting in Norway

One of the highlights of 2025 was the DI meeting in Norway. It was a wonderful opportunity to meet as a community in a beautiful setting and to share our progress and ideas in person once again. The Slovak team contributed to the workshop section with the session "Evaluating the Modules," led by Professor Andrea Madarasová Gecková. Together, we deepened our understanding of how evaluation processes can be improved and developed joint approaches for assessing project webpages. During the meeting, Ján Hlodák presented the ongoing project on the experiences of patients with chronic kidney disease undergoing dialysis treatment. The presentation received positive feedback from the community, confirming the importance of this topic. The team also presented a short video prepared by Lucia Bosáková, reflecting on our experiences in the Czech Republic and exploring what it means to be a DI member.

New PhD Students

In September 2025, our team welcomed two new PhD students. Katarína Csonková, supervised by Lucia Bosáková, has joined the module focusing on the experiences of parents of children having mental health problems. At Comenius University in Bratislava, Dominika Kunová, supervised by Katarína Greškovičová, became part of the team working on the project exploring birth experiences. We are very pleased to have Katarína and Dominika with us and wish them both success in their research and future academic work.

Publications

Hlodák, J., Madarasová Gecková, A., Dankulincová Veselská, Z., & Feketeová, E. (2025). The burden of narcolepsy symptoms from patients' perspective: a narrative qualitative study. Sleep and Breathing, 29, 231. https://doi.org/10.1007/s11325-025-03407-y

Singapore

By Laurie Goldsmith

Greetings from Singapore (Laurie Goldsmith, Jose Maria [Chema] Valderas, Nithya Palanivelu, Mariel Maniclang, Foon Leng Leong, Rabikah Yahya, Wee Ling Koh, and Binglong Lee) where we are very pleased to be reporting on our first year of formal operation. Most importantly, we received our DIPEx accreditation in November 2024 under the banner “Health Experiences Singapore” (HEXI-SG) and jointly supported by the Division of Family Medicine and the Centre for Research in Health System Performance (CRiHSP) at the Yong Loo Lim School of Medicine, National University of Singapore. We have been busy formally and informally sharing about HEXI-SG, applying for grants, sorting out our local operations, and starting our initial research projects. Along the way we’ve educated Institutional Review Board reviewers, made some new local friends, had fun with creating a logo and brainstorming about a tagline, and welcomed new staff. A notable and recurring part of the adventure of our first year has been addressing skepticism that Singaporeans will really consent to be video recording for potential showing on the web. We find it very helpful to respond by showing the DIPEx Japan website and the Japanese men who were willing to discuss their prostate cancer. (Thanks DIPEx Japan for your groundbreaking in Asia and thanks to those study participants who were willing to be video recorded!) And, of course, a personal highlight of this year for Laurie was attending the 2025 DIPEx International Collaborators meeting in Tromsø where it was a delight to meet and learn from everyone.

Presentations

On behalf of our team, Laurie shared about HEXI-SG and our immediate plans in two presentations: one in October 2024 at the Family Medicine Research Forum, Yong Loo Lin School of Medicine, National University of Singapore, and another in September 2025 at 12th National Cancer Institute Singapore Annual Research Meeting in a Satellite Symposium titled “Catalysing Cancer Research in Primary Care: Implications for Primary Care Practitioners.”

Grant Proposals

So far, we’ve not been successful at receiving a competitive research grant for our activities. But we keep trying, including putting into practice the advice Laurie received from others at the 2025 DIPEx International Collaborators meeting to try including a HEXI module within a larger study. We’re still waiting to hear on grant submissions using that approach. We’ve submitted grant applications for HEXI-SG research on Singapore’s four most common cancers (colorectal, breast, lung, and prostate), menopause, high blood pressure, diabetes, and healthy ageing, and are in the process of another grant application studying multimorbidity. We’ve applied to research competitions offered internally in our university and our health region as well as external competitions offered by the Tanoto Foundation (a local health charity), Singapore’s National Medical Research Council, and Singapore’s Ministry of Education. We were particularly disappointed to not receive funding through a University of Sydney/National University of Singapore funding call (with Katherine Kenny [HEXI Australia co-lead] as the University of Sydney Chief Investigator) as the proposal included funding support for the first Asia-Pacific HEXI regional meeting.

Fingers crossed that one or more of the four grant submissions currently under review and the grant submission currently under preparation are successful. In the meantime, we're busy working on our colorectal cancer pilot module (with enough funds for 20 interviews in English-language only) and our recurrent urinary tract infection module (with enough funds for 35 interviews in total, including translation costs to have 12 of the 35 interviews be conducted in one of Singapore's other three official languages [Malay, Mandarin, and Tamil] and then translated to English for analysis purposes). Dr Binglong Lee, a family medicine physician doing his fellowship, will also undertake a healthy ageing module for his fellowship research project (with a minimum of 20 English-language interviews; additional interviews and languages depend on the success of a grant under review).

One of the grant competitions to which we applied was a call for interventions to address healthy ageing. Inspired by how HEXI data has been used to create films, we suggested that HEXI healthy ageing narratives could be used for an anti-ageism campaign film and evaluated for its effectiveness in expanding knowledge and changing ageing beliefs held by the public, providers, and policy makers. We've not yet convinced a funder to support this idea (have tried three times and heard two no's so far with a third decision pending), but we share the HEXI film-as-intervention idea here in case it's helpful to others.

HEXI-SG's website

We are close to being able to launch the HEXI-SG website, with examples of what a future Singapore module would look like using portions of Health Experiences Canada's breast cancer module. Ends up it's complicated to purchase a ".sg" domain within a university setting but we've persevered and are now on the cusp of purchasing our preferred domain. A few weeks after that purchase is complete, our website will be live and linked to HEXI International.

Spain

By Emilio Sanz and Vinita Mahtani

Dear friends,
The latest news from Spain is the development of projects involving DIPEx data into medical education:

1. Training Intervention on intimate partner violence for primary care professionals: an approach based on women's experiences. This project, which is Alejandra's doctoral dissertation, consists of developing a training intervention on intimate partner violence for primary health care professionals. The development of this intervention is based on the Gender-Based Violence Module of DIPEx Spain, where it was found that the women participants expressed a need for training for healthcare professionals. This was complemented and supported by scientific literature on training in gender-based violence for healthcare professionals in Spain, and it was decided to develop training that could, in some way, contribute to this aspect. The experiences of the women participating in the module will guide both the perspective and design of the training intervention, as well as its content. In addition, the training intervention will be evaluated quantitatively through a pre-post study with a control group, using the validated Physician Readiness to Manage Intimate Partner Violence Survey (PREMIS) instrument, and in parallel with a qualitative evaluation of the perception of change in healthcare personnel who have been exposed to the training intervention, using reflective documents.
2. Development and Evaluation of a Person-Centered Practice Training Intervention for Primary Care Professionals: An Approach Based on Patient Narratives. This project, the doctoral dissertation of María Elisa Torres Tejera, aims to develop a training intervention in person-centered practice (PCP) for primary care physicians and nurses in the Canary Islands. The proposal seeks to promote a more empathetic and personalized approach to healthcare, grounded in the real experiences of patients collected through the DIPEx Spain project. The intervention will be delivered as a MOOC, structured into four training modules: exploring illness and disease, understanding the person as a whole, building a shared project, and strengthening the doctor–patient relationship. It will be evaluated using a mixed-method design that combines quantitative and qualitative approaches, employing the PPOS and ACPAPS questionnaires together with the analysis of participants' reflective journals. The project is supported by funding from both a FIISC scholarship and the Francesc Borrell Grant.

AYUDA PARA PROYECTOS DE INVESTIGACIÓN
"FRANCESC BORRELL" 2025

en Convocatoria General

El Comité del XXXIV Congreso de Comunicación y Salud de la semFYC, celebrado en Girona los días 20, 21 y 22 de marzo de 2025, certifica que el trabajo titulado:

Investigación, desarrollo y evaluación de una intervención de práctica centrada en la persona para profesionales de atención primaria: una aproximación basada en narrativas de pacientes

Autoras: María Elisa Torres, Vinita Mahtani

ha sido el Ganador de la Convocatoria General de Ayudas para la realización de Proyectos de Investigación "Francesc Borrell" 2025, correspondiente a una dotación de 1.500 €.

Girona, 22 de marzo de 2025

María

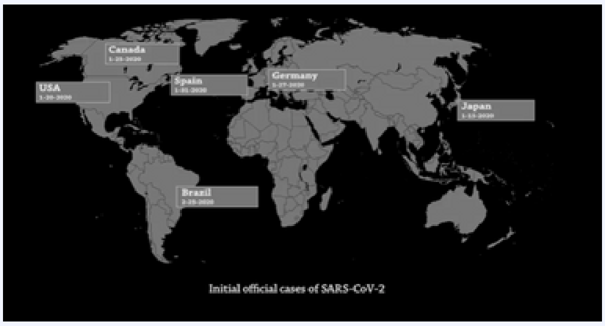
Josep Maria Bosch Fontcuberta
Coordinador Comité Organizador

María Rodríguez Barragán
Coordinadora Comité Científico

ONGOING PROJECTS

1. The launch of the Intimate partner gender violence module will be in the first semester of 2026. Topic summaries are almost finished and we are working on the edition of clips.

2. Due to overload of projects, we have a delay with the launch of the DIPEx Covid-19 module, which is ongoing. Although we have new products as the collaboration in a book about long-covid, where we were asked to include with DIPEx Spain data information about personal experiences for a person centered care. (V Mahtani, C Real, V Expósito in Investigación en COVID persistente desde el ámbito asistencial: lo que se ha hecho, lo que queda por hacer. Editors L Sagarra, R Magallón, A Aguilar, 2024, ISBN 978-84-1070-270-7). This project, funded by the Spanish Ministry of Science (Health Institute Carlos III), includes an arts-based knowledge transformation. We have finished the Documentary called "A margullar" including international participants from USA, Canada, Germany, Japan, Brazil and Spain. This was shared, commented on and improved after our meeting in Norway. We are planning to have a version with subtitles in Japanese which is very exciting!



3. We have finished the ABKT project related to the Intimate partner gender violence module funded by the Spanish Ministry of Equity. This project is part of the doctoral dissertation of Jessica García, who will hopefully get her degree very soon. https://www.musaexperience.com/la-tela-de-ara%C3%B1a. This project was presented also at the "Congreso Mundial con la Infancia y Adolescencia" celebrated in November 2024.

KNOWLEDGE TRANSLATION AND DISSEMINATION

We continue disseminating our website linked to DIPEx Spain called MUSA experience, available at: https://www.musaexperience.com/; where many of the HEXI members are included as it is part of our MUSA International project. You are all invited to help construct the contents of this website with artistic transformations of your research and publications, as we have a section for our own projects and a section where we add exciting information on this topic of arts-based knowledge transfer. We continue to pursue funding for this type of project.

Based on the Palliative care module we have had the visit of Aina Camps who is an internal medical resident specialising in preventive and public health this year. She has developed a theatre script around the topic of death in order to work all the taboo related to death and dying. Soon it will be available on our website and this is a picture of the dramatized reading we did in a theatre workshop.

OTHER NEWS

We are still trying to collaborate with the international module about Ukrainian refugees, trying to get researchers to support this work.
In 2024, Mario Martín Labrador spent two months as an academic visitor at the University of Oxford, working with the Nuffield Department of Primary Care Health Sciences. Later, he joined Kyoto University, where he collaborated with the DIPEx Japan team and was invited to speak at the Annual Conference of Midwives in Kyoto, sharing his clinical experience and reflecting on gender roles in the midwifery profession. Both stays were a highly enriching experience, allowing him to strengthen international collaborations and broaden his academic perspective.

We were delighted to attend the DI meeting in 2024 ONLINE and in Norway in 2025 were we shared interesting discussion around the topic of Euthanasia thinking on an international HEXI module; also, the topic around person centered care using DIPEx material and the international collaboration about the role and impact on the interviewer, for example when she/he is a health care professional. Following this meeting we have set a group working on this topic along with other HEXI partners, hopefully you will hear from us soon!
Finally, collaborating with DIPEx Brasil in the creation of the “Red Iberoamerica de Investigación Cualitativa en Salud” (Iberoamerican network for qualitative research in health, which will be officially formalized in Santiago de Chile in November 2025.
We are still involved in some other issues, but we think that all these projects would be enough to keep you interested. Please feel free to contact us if you are interested in any of those projects. Moreover, we expect to see you all again in Germany next time!
3.

Switzerland - www.DIPEx.ch

By Andrea Glässel

Dear colleagues,

In this year's newsletter, we would like to share with you the following highlights from the 2024/25 projects of our Swiss DIPEx group, which consists of Nikola Biller Andorno, Andrea Radvanszky, Beatrix Göcking, Giovanni Spitale, Corine Mouton Dorey, Dirkje Swennen, Isabel Zwahlen, Lea Stucki, Wilfried Kohrs, and Andrea Glässel.

We had a wonderful and very intense meeting with you in Tromsø in June, which we talked about for a long time afterwards and which still motivates us today.

We are delighted that two new modules have been funded by the Swiss National Science Foundation (SNSF).

Project for Module 1: Towards human-centered healthcare: Understanding, measuring, and promoting shared care configuration (CCC) as a mutually beneficial interaction between healthcare professionals and patients. The module focuses on shared healthcare configuration. We are very excited about this. It is our first module that does not deal with diseases. Led by Prof. Georg Bauer UZH and partners from ZHdK, the Institute for Design Research (IDF) (DHDLL) and ZHAW. https://data.snf.ch/grants/grant/10003791 – We welcome our new doctoral student Isabel Zwahlen to the project and to DIPEx.

Project for Module 2: Support and counseling for access to healthcare with resources for self-determination and shared decision-making in cases of variations in sex characteristics/intersexuality (SHARED-VSC). Led by PD Dr. med. Jürg Steuli IBME, University of Zurich, and Dr. Cynthia Kraus, University of Lausanne, as well as other partners. https://data.snf.ch/grants/grant/227305 . We welcome our new PhD student Dirkje Swennen to the project and to DIPEx.

We are working on a third SNF-funded project across modules as part of a secondary analysis on the topic of “Ethical dimensions of digitally supported physiotherapy: foundations for ethics training for physiotherapists” https://data.snf.ch/grants/grant/220690 with the Zurich University of Applied Sciences, Institute of Physiotherapy, on a DIPEx cross-module evaluation method developed by Dr. Giovanni Spitale.

We are also part of the European application for the THSC 2025 call for proposals “Better care closer to home: improving primary and community care” led by Vinata and Emily, involving a total of six DIPEx countries: Spain, Canada, Norway, the Netherlands, Czechia, and Switzerland. It has been a very intensive collaboration, which we are very happy about. Please keep your fingers crossed for us that we receive a positive response.

The Parkinson's module is in the starting blocks for publication on the website. It's great that these experiences will soon be visible. The intensive care module has been expanded to include several categories. A big thank you to our two colleagues Dr. Susanne Jöbges and Dr. Corine Mouton Dorey. The content from the Beatrix pilot study has also been prepared and is about to be published on the website.

Since 2022, the DIPEx project has been an important part of the structural development project Digital Health Design Living Lab – DHD LL (www.dhdLL.ch), which brings together three Swiss universities across institutions on the topics of ethics, design, health, and care to support digital transformation in the Zurich area: the Institute for Design Research (IDF) at Zurich University of the Arts (ZHdK), the Institute for Biomedical Ethics and History of Medicine (IBME) at the University of Zurich (UZH), and the Institute of Public Health (IPH) at Zurich University of Applied Sciences (ZHAW).

DIPEx in teaching

We are currently working on two ncollaborating with the IBME (UZH) to develop a new interprofessional learning program for students in the health professions (physiotherapy, occupational therapy, midwifery, nursing, and health promotion and prevention) at the IHP (ZHAW), which uses the DIPEx database and innovative, human-centered design methods. The individual experiences of DIPEx serve as a starting point for developing questions and solutions on the fundamentals of good healthcare. We will present this for the first time in January as part of the Winter School at ZHAW.

<u>Virtual Patients: A training module in Shared Decision-Making for medical students based on DIPEx patient narratives</u> (Andrea Radvanszky – Giovanni Spitale – Nikola Biller-Andorno)

Since early 2025, the Swiss DIPEx team has been developing two Virtual Patient (VP) exercises for medical students at the University of Zurich, based on patient interviews from DIPEx Switzerland. The project is funded by the University of Zurich’s Teaching Development Fund (Universitäre Lehrförderung, ULF) open innovation program, with matching funds from the UZH Foundation. It runs over a two-year period.

The goal is to develop two tailored exercises for the Zurich Clinical Reasoning Tool: in the bachelor’s program, the focus lies on communication skills; in the master’s program, on shared decision-making. Both exercises are integrated into the longitudinal communication curriculum of the UZH medical program, allowing students to practice independently in a safe, low-pressure environment. This approach addresses the limited availability of real patient encounters in medical education and the growing number of students.

The VPs are based on patient narratives collected through the DIPEx Switzerland project, which documents authentic illness experiences across diverse conditions and backgrounds. By engaging with these virtual patients, students are exposed to a wide range of realistic, nuanced scenarios they might not otherwise encounter during their training. Although the patient interviews were conducted in the context of specific illnesses (e.g., young patients with haemato-oncological diseases), the exercises are designed around dimensions that go beyond individual conditions, addressing communicative and ethical challenges relevant across a broad range of clinical situations.

Interview excerpts describing negative experiences—instances where communication or shared decision-making went poorly—are didactically valuable. However, patient learning processes are an equally important design dimension. Patients (for example younger ones) may initially be unfamiliar with communicating with healthcare professionals and gradually learn to open up or prepare questions for their consultations. Such learning trajectories are reflected in the virtual exercises by modulating the characteristics of the virtual patient. This enables students to practice, for instance, informing in an age-appropriate manner, slowing down conversations in stressful situations to avoid blocking the patient’s communication, or ensuring mutual understanding.

To ensure technical robustness and scalability, the project integrates its content with SimConverse, a leading international simulation platform already used by major universities and healthcare systems. This partnership enables unscripted, AI-driven conversations, real-time automated feedback, and analytics to track student progress.

Publications:

Gabathuler, F., Würth, K., Hodel, M., Glässel, A., Biller-Andorno, N., & Schwind, B. (2025). Reflections on epistemic injustice to advance person-centred care through the experiences of persons with chronic pain. Journal of Bioethical Inquiry. Advance online publication. https://doi.org/10.1007/s11673-025-10457-0

Keiser, S., Schwind, B., Biller-Andorno, N., & Glässel, A. (2025). People with chronic pain in Switzerland: Patients' and health professionals' perspective on potentials of outpatient health care. International Journal of Health Professions, 11(1), 174–185. https://doi.org/10.2478/ijhp-2024-0013

Glässel, A., & Hippold, I. (2024). Exploring patient perspective: Using narrative DIPEx interviews and the ICF model for interprofessional learning. Frontiers in Rehabilitation Sciences, 5, 1424370. https://doi.org/10.3389/fresc.2024.1424370

Ribi, K., Schöpf-Lazzarino, A., Visscher, R. M. S., Jurisic, J., Alder, E., & Schwind, B. (2024). Chronic illness and financial burden in Switzerland (FINK): A protocol for a mixed methods research project. BMJ Open, 14(11), e089743. https://doi.org/10.1136/bmjopen-2024-089743

Link separated:
Since 2022, the DIPEx project has been an important part of the structural development project Digital Health Design Living Lab – DHD LL (www.dhdLL.ch), which brings together three Swiss universities across institutions on the topics of ethics, design, health, and care to

United Kingdom

By Lisa Hinton

We were delighted that ten of us from the UK were be able attend the splendid meeting in Tromso (thank you dear Norwegian colleagues). Unsurprisingly several of us spent quite a lot of time in the refreshing sea (see photos)

Members of the UK group included Lisa Hinton, Ruth Sanders, Catherine Pope, Sharon Dixon, Kate Sheridan, Bakita Kasadha, Tori Ford, Abi McNiven, Sue Ziebland and our University of Stirling colleague, Kate Hunt.

We thoroughly enjoyed the opportunity to connect with our wonderful international colleagues and dig deep into our shared methods with the most inspiring and collaborative group of people we know.

Sue Ziebland has recently stood down from representing the UK on the Board and Lisa Hinton has kindly agreed to take on representing the UK. Tori Ford from the UK group is vice chair of the International group and Sue will continue as an advisor to the officers during the transitions to the new chair and secretary.

We are sorry to report that we do not yet have a final agreement with the former published of the UK's Healthtalk and Socialcare talk platforms but in the meantime our material is all available on hexi.ox.ac.uk.

Several of our studies are now complete and either published or awaiting publication:

Knee replacements in the context of comorbidities (co PI Abi McNiven)
Recurrent vaginal thrush (Tori Ford's DPhil)
Dementia and dementia carers (Suzanne Ii)
Living with dementia and memory problems (Lyndsay Lindley- York University and Suzanne Ii) Published on socialcaretalk.org

CURRENT - due for publication 2026-27
Painful periods (Sharon Dixon's DPhilresearch)
Care Leavers (including refugees/ migrants) (Suzanne Ii / Sue Ziebland)
Stillbirth (Danya Bakhbakhi's doctoral research)
Mesh- breast reconstruction (Rachel Rolph's DPhil research)
High blood pressure in pregnancy (Layla Lavallee's DPhil research)
Endometriosis (PI Abi McNiven)
Lived experience researchers (Bakita Kasadha's doctoral research)

RECENTLY funded
Asylum seekers (led by colleagues in University of York, collaboration with Oxford)
Experiences of pregnancy, postnatal and intrapartum care to tackle inequalities (Lisa Hinton's NIHR Advanced Fellowship)

NEW proposals, under consideration by funders
Vaping (maximising rapid access to understandings of contemporary adult vaping pathways Application to Chief Scientist Office Scotland Kate Hunt, Ashley Brown Alice MacLean et al)
Egg Freezing (PI Lisa Hinton, with Kate Sheridan, Tori Ford et al NIHR Research for Patient Benefit, Stage 2 under review)

New publications since last newsletter:
Tori Ford, T., Talbot, A., Hayward, G., Tonkin-Crine, S., Ziebland, S., & McNiven, A. (2024). Managing recurrent vulvovaginal thrush from patient and healthcare professional perspectives: A systematic review and thematic synthesis. Patient Education and Counseling, 118, 108004. https://doi.org/10.1016/j.pec.2023.108004

Tan, J. Y., Ford, T., McNiven, A., & McPherson, T. (2025). Sex, intimacy and psoriasis: A qualitative study exploring young people's experiences. Journal of the European Academy of Dermatology and Venereology.https://doi.org/10.1111/jdv.20756

In press:

- Ford, T., Ziebland, S., Hayward G,, Tonkin-Crine, S., & McNiven, A. Attending to Gynecology: Managing the ‘mess’ of recurrent vulvovaginal thrush. Sociology of Health & Illness.
- Abi Wanat, M., Weller, S., Borek, A. J., Newhouse, N., & McNiven, A. (2024). Crafting Tempo and Timeframes in Qualitative Longitudinal Research: Case Studies From Health Research. International Journal of Qualitative Methods, 23. https://doi.org/10.1177/16094069241270399 (Original work published 2024)
- MacLellan, J., Dixon, S., Toye, F., & McNiven, A. (2024). Unpacking complexity in addressing the contribution of trauma to women’s ill health: A qualitative study of perspectives from general practice. British Journal of General Practice, 74(e604–e609). https://doi.org/10.3399/BJGP.2024.0024
- McNiven, A., Dobson, A., Read, K. and Dixon, S. (2025) ‘My patients are “gunning for a fight” that I don’t want’: reflecting on feeling dismissed and conflict-expectant consultations, British Journal of General Practice, 75 (754), pp.234-236. doi.org/10.3399/bjgp25X741561
- Sharon Dixon S, Evans E, Vincent K, Toye F, McNiven A, Hinton L. 'I think it is helpful… I mean it's not always helpful': diagnostic complexity in endometriosis. The British journal of general practice: the journal of the Royal College of General Practitioners. 2025 Jun 23: British Journal of General Practice
- Dixon, S., Hirst, J., Taghinejadi, N., Duddy, C., Vincent, K., & Ziebland, S. (2024). What is known about adolescent dysmenorrhoea in (and for) community health settings? Frontiers in Reproductive Health, 6, 1394978. https://doi.org/10.3389/frph.2024.1394978
- De Silva P M, Dixon S, Vekaria G. Restructuring endometriosis care BMJ 2024; 387 :q2416 doi:10.1136/bmj.q2416
- Dixon, S., Taghinejadi, N., Duddy, C., Holloway, F., Vincent, K., & Ziebland, S. (2024). Adolescent dysmenorrhoea in general practice: Tensions and uncertainties. Frontiers in Reproductive Health, 6, 1418269. https://doi.org/10.3389/frph.2024.1418269
- Khan, Z., Vincent, K., Rai, T., & Dixon, S. (2024). A lack of sociodemographic participant diversity in endometriosis evidence risks unrepresentative clinical guidance: A structured review of the evidence contributing to a NICE guideline. British Journal of General Practice 74. https://doi.org/10.3399/bjgp24X737697
- Dixon, S., Taghinejadi, N., Holloway, F., Papanikitas, A., & Vincent, K. (2024). Supporting teenagers with period pain in general practice: Clinical review. British Journal of General Practice 74, 283–285. https://doi.org/10.3399/bjgp24X738489
- Dixon, S., Mawson, R., Kirk, U. B., & Horne, A. W. (2024). Endometriosis: Time to think differently (and together) British Journal of General Practice 74, 200-201. https://doi.org/10.3399/bjgp24X737085
- Lisa Moxon S, Graham W, Filippi V, Blencowe H, Doherty T, Kabakian-Khasholia T, Kumar M, Oluoch D, Hinton L. Nothing about us without us: Consolidating experiences of maternity care to advance equity. British Journal of Obstetrics and Gynaecology, (Accepted 1 July 2025) http://dx.doi.org/10.1111/1471-0528.18300
- Maluni J, Oluoch D, Molyneux S, Boga M, Jones C, Murila F, English M, Ziebland S, Hinton L. After neonatal care, what next? A qualitative study of mothers’ post-discharge experiences after premature birth in Kenya. International Journal for Equity in Health. 2025 Jan 20;24(1):17.
- Maclean, A., Driessen, A., Hinton, L., Nettleton, S., Wild, C., Anderson, E., Brown, A., Hoddinott, P., O’Dwyer, C., Ziebland, S., & Hunt, K. (2025). Rethinking ‘Recovery’: A comparative qualitative analysis of experiences of intensive care with COVID and Long Covid in the United Kingdom. Health Expectations, 28(2), Article e70253. https://doi.org/10.1111/hex.70253

- Driessen, A., Navarro de Souza, A., Pfeiffer Castellanos, M. E., Tuma de Oliveira, M. V., Lima Carvalho, E., & Hinton, L. (2024). Navigating uncertainties in critical care with COVID-19: A cross-country analysis of patient narratives from Brazil and the United Kingdom. SSM – Qualitative Research in Health, 5, 100363. https://doi.org/10.1016/j.ssmqr.2023.100363
- BakitaKasadha, B., Tariq, S., Freeman-Romilly, N., Pope, C., Namiba, A., Nyatsanza, F., Hinton, L., & Rai, T. (2024). "We decided together": A qualitative study about women with HIV navigating infant-feeding decisions with the father of their children. BMC Pregnancy and Childbirth, 24(1), 41. https://doi.org/10.1186/s12884-023-06198-w
- Kasadha, B., Tariq, S., Namiba, A., Freeman-Romilly, N., Moepi, N., Letting, G., & Rai, T. (2025). Hearing the silence and silenced: Co-producing research on infant-feeding experiences and practices with Black women with HIV. Sociology of Health & Illness, 47(1), e13871. https://doi.org/10.1111/1467-9566.13871
- Kasadha, B., Hinton, L., Tariq, S., Nyatsanza, F., Namiba, A., Freeman-Romilly, N., & Rai, T. (2024). How women living with HIV in the UK manage infant-feeding decisions and vertical transmission risk – a qualitative study. BMC Public Health, 24, Article 2130. https://doi.org/10.1186/s12889-024-19581-9
- Tanvi Rai, T., Dowrick, A., Qureshi, K., Munro, H., Wild, C., Douglas, J., Ziebland, S. (2024) How should we do racially just research? Learning from a qualitative study on Covid-19 pandemic experiences in the UK. Journal of Critical Public Health: 1 (2) https://doi.org/10.55016/ojs/jcph.v1i2.77774
- Anna Dowrick, A., MacLean, A., Ziebland, S., & Greenhalgh, T. (2025). Trust in Transition: Exploring Changing Trust in Vaccination in the Context of Long Covid in the United Kingdom. Health expectations : an international journal of public participation in health care and health policy, 28(5), e70459. https://doi.org/10.1111/hex.70459
- *Dowrick, A., Qureshi, K., & Rai, T. (2025). Speculating About Futures with Covid Reinfection in the UK: The Body as a Site of Educated Guesswork. Medical anthropology, 1–12. Advance online publication.* https://doi.org/10.1080/01459740.2025.2461305
- *Heath, J., Moran, M., Dowrick, A. (2024) Examining qualitative cross-country comparative analysis in health: Reflective insights and methodological considerations. SSM – Qualitative Research in Health. 5: 100416*
- *Dowrick, A., Qureshi, K., & Rai, T. (2024) Negotiating un/sanitary citizenship: the reception of UK government COVID-19 public health messaging by racialised people highly exposed to infection, Anthropology & Medicine, DOI:* 10.1080/13648470.2023.2274710
- Sue Ziebland, S., Sakuma-Sato, R., Grob, R., Dowrick, A., Navarro Dias de Souza, A. R., Spitale, G., & Schlesinger, M. (2024). Cross-country analysis of qualitative interviews: Developing a method, a community and an understanding of how COVID has been experienced around the globe. SSM – Qualitative Research in Health, 5, 100396. https://doi.org/10.1016/j.ssmqr.2024.100396
- Hunt, K., Maclean, A., Locock, L., O'Dwyer, C., Nettleton, S., Ziebland, S., & Wild, C. (2024). Young adults' experiences of biographical retrogression whilst living with long COVID. Sociology of Health & Illness, 46, 1526–1546. https://doi.org/10.1111/1467-9566.13798
- Wild, C., Maclean, A., Nettleton, S., Hunt, K., & Ziebland, S. (2024). The double invisibility of Long Covid in children. Social Science & Medicine, 347, 116770. https://doi.org/10.1016/j.socscimed.2024.116770
- Maclean, A., Wild, C., Hunt, K., Nettleton, S., Skea, Z. C., & Ziebland, S. (2023). Long Covid and young people: A qualitative study. BMJ Open, 13, e075756. https://doi.org/10.1136/bmjopen-2023-075756