

Workshop: Produção de narrativas pessoais de adoecimento como evidências qualitativas na pesquisa, formação e educação permanente, e cuidado em Saúde

NARRATIVAS E SAÚDE

Database of Individual Patients' Experience of Illness

DIPEX International

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História

A idéia de uma **Base de Dados de Experiências Individualizadas de Pacientes sobre o Adoecimento** (DIPEX = **D**atabase of **I**ndividual **P**atients' **E**xperience of **I**llness) foi originalmente de Ann McPherson, uma GP de Oxford e escritora, e de Andrew Herxheimer, farmacologista clínico e membro emérito da colaboração Cochrane. Em 2000, nasce o projeto no Reino Unido com publicação no *Lancet*, inauguração do website em 2001 que, atualmente, inclui 100 módulos sobre diferentes condições de saúde e doença. A investigação é conduzida pelo *Health Experiences Research Group* (HERG) situado no Departamento de Atenção Primária e Ciências da Saúde da Universidade de Oxford.

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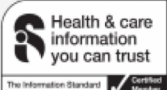
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Related:

- Find out how we can help you
- Friends, family and carers
- NEW: Giving up smoking




Support, encouragement, empathy is best when it comes from someone in the same situation as you.

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Our patient experience videos are great, free resources for teaching & training

Related:

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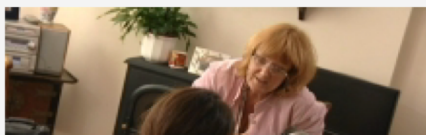
It takes students out of the lecture theatre to see real, lived experiences.

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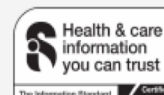


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A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

A.L.S

AIDS (acquired immune deficiency syndrome)

Abortion for fetal abnormality

Abortion: young people's views (in 'Sexual Health') (Young People)

Ageing (link to later life category)

Alcohol: young people's experiences (Young People)

Alport Syndrome

Alzheimer's disease: carers of people with

Amyotrophic lateral sclerosis

Anemia, sickle cell in young people (in 'Long term health conditions') (Young People)

Angina (in 'Heart failure')

Anorexia Nervosa (young people) (Young People)

Antenatal Screening

Antenatal screening: for sickle cell and beta thalassaemia

Antenatal screening: general

Antidepressants

Arthritis in young people (Young People)

Arthritis in young people (in 'Long term health conditions') (Young People)

Arthritis: rheumatoid

Asperger's syndrome: parents' experiences

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- INTENSIVE CARE
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DRUGS AND ALCOHOL

EATING DISORDERS

ECZEMA

EPILEPSY

HEALTH AND WEIGHT


PSORIASIS

LONG TERM HEALTH CONDITIONS

SEXUAL HEALTH

DIABETES TYPE 1

Search




It gives us a unique look at what it's like to be on the receiving end.

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História

Colegas da Alemanha, Espanha, Japão, Coréia, Canadá e Austrália participaram de conferências e treinamento com membros do HERG de forma a poder estabelecer projetos semelhantes em seus próprios países. Todos os sites DIPEX nos diversos países permitem acesso livre a todo seu conteúdo e são amplamente utilizados por pacientes, familiares, profissionais de saúde em formação, bem como professores e pesquisadores.

Encorajados pelo interesse mundial por esta abordagem de publicar a pesquisa sobre a experiência de pacientes em um formato altamente acessível, os grupos fundadores iniciaram reuniões anuais em 2010 e, finalmente, estabeleceram a *DIPEX International* (DI) em 2013.




Health information for the public and professionals, based on research.

DIPEX International is an association of academic and non-profit groups around the world, committed to improving understanding of health and illness experiences globally.

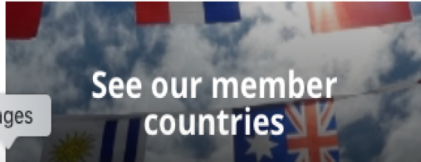
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Pages



See our member countries



Read about our latest news

História

Em setembro de 2011, em Prato (Itália), foi realizado um workshop sobre emoções e doenças crônicas, cuja pesquisa foi publicada em um número especial da revista *Chronic Illness*, em 2012. Um artigo sobre dor crônica em diferentes contextos culturais ilustra a potencialidade da rede Dipex em estudos transculturais. Além da análise temática de conteúdo para preparar o material para o website, as entrevistas podem ser objeto de análise por distintos referenciais teóricos, conforme ilustrado neste número que contém artigos com abordagem socio-linguística, fenomenológica, entre outras.

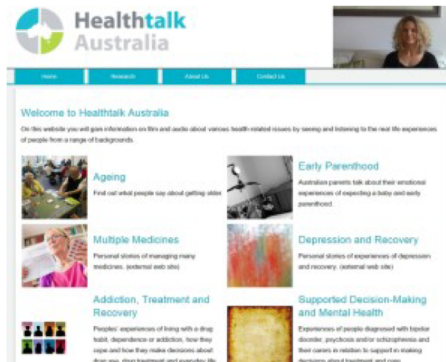
Seguiram-se reuniões em Oxford (2012), Doha (2013), Kyoto (2014), Freiburg (2015), Tenerife (2016) e Montreal (2017). Atualmente, 13 países integram a rede *Dipex International*.

Our Members

[Australia](#)[Canada](#)[Czech Republic](#)[Germany](#)[Israel](#)[Japan](#)[Netherlands](#)[Norway](#)[Republic of Korea](#)[Spain](#)[Switzerland](#)[United Kingdom](#)[USA](#)

DIPEX International (DI) is comprised of academic partners who bring considerable breadth and depth of perspective to the data collection, analysis and dissemination of our research. DI member teams are based within accredited University centres and led by senior scientists covering a range of disciplines in the health sciences including sociology, psychology and more generally, health services research.





Australia

Name of group: Healthtalk Australia

Organisational base: Monash University, University of Sydney, University of New South Wales.

Web Address: healthtalkaustralia.org

Established: 2012

Modules completed: Depression and recovery, Living with multiple medicines, Emotional experiences of early parenthood, Experiences of ageing

Modules in progress: Supported decision making and mental health, Experiences of addiction, treatment and recovery



Canada

Name of group: Health Experiences Research Canada

Organisational base: St. Mary's Research Centre, St. Mary's Hospital

Web address: www.healthexperiences.ca

Established: 2010

Modules completed: caregiving

Modules in progress: breast cancer



Czech Republic

Name of group: DIPEX Czech Republic

Organisational base: Olomouc University Social Health Institute (OUSHI), Palacký University Olomouc

Web address: hovoryozdravi.cz

Established: 2015

Modules completed: Health and lifestyles of seniors

Modules in progress: Quality of life of palliative patients, Spirituality and health in adolescents and adults in the Czech Republic, Breast Cancer



Germany

Name of group: DIPEX Germany

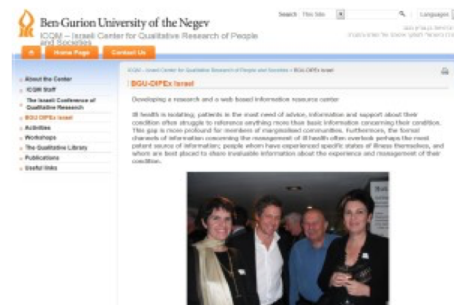
Organisational base: Universities of Freiburg and Göttingen

Web address: krankheitserfahrungen.de

Established: 2008, website launch 2011

Modules completed: type 2 diabetes, chronic pain, epilepsy, chronic inflammatory bowel diseases

Modules in progress: breast cancer, prostate cancer, colorectal cancer, rehabilitation



Israel

Name of group: The Israeli Center for Qualitative Research of People and Societies

Organisational base: Ben Gurion University of the Negev

Web address: in.bgu.ac.il/en/icqm/Pages/BGU-DIPEX-Israel.aspx

Established: 2013

Modules completed: Chronic Pain



Japan

Name of Group: DIPEX Japan

Organisational base: Non-profit organisation

Web address: dipex-j.org

Established: 2007 (website launched 2009)

Modules completed: breast cancer, prostate cancer, dementia (individuals and family members), bowel cancer screening

Modules in progress: clinical trials, chronic pain, oral health & care

정병철이아기
INTERNATIONAL



| Republic of Korea

Name of group: DIPEX Korea

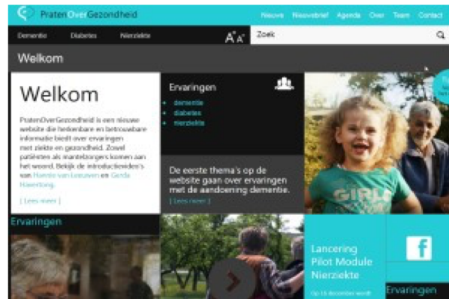
Organisational base: Department of Humanities, Seoul National University

Web address: healthstory4u.co.kr

Established: 2007

Modules completed: diabetes, breast cancer, stomach cancer, depression, hospice care

Modules in progress: dementia



Netherlands

Name of group: Praten Over Gezondheid (Talking About Health)

Organisational base: Stichting PratenOverGezondheid

Web address: pratenovergezondheid.nl

Established: 2013

Modules completed: dementia – patient and carer perspectives

Modules in progress: type 2 diabetes, chronic kidney disease, rare diseases, visual impairment, metastatic breast cancer, palliative care for children.



Norway

Name of group: Helsesnakk, DIPEX Norway

Organisational base: Norwegian centre for e-health research

Web address: helsesnakk.no (coming soon)

Established: 2015

Modules in progress: Muscular diseases (pilot module), Mental health – patient and carer perspectives.



Spain

Name of group: DIPEX Spain

Organisational base: Non for profit scientific society according to the Spanish law

Web address: dipex.es

Established: 2010

Modules completed: diabetes, palliative care (patients' perspective)

Modules in progress: palliative Care (family and relatives' perspectives) hypertension, reproductive technologies



United Kingdom

Name of group: DIPEX Charity

Organisational base: Registered UK charity

Web address: healthtalk.org

Established: 2001

Modules completed: 90+ conditions covered!

Coming soon...



USA

Name of group: Health Experiences Research Network

Organisational base: University of Wisconsin-Madison; Johns Hopkins University; Oregon Health and Sciences University; Yale University

Web address: healthexperiencesusa.org

Established: 2014

Modules in progress: Young Adults' Experiences with Depression; Traumatic Brain Injury in Veterans (pilot module)

Objetivos

A DIPEX Internacional é uma associação de pesquisadores que realiza pesquisa sobre a experiência de adoecimento. Sua missão é desenvolver o entendimento das experiências de saúde e adoecimento em diferentes países para o benefício de comunidades, pesquisadores, profissionais de saúde e gestores. A DIPEX pretende ser potencialmente útil para:


- Informação e suporte a pacientes e cuidadores
- Educação clínica e desenvolvimento profissional
- Melhoria da qualidade do cuidado
- Atendimento centrado no paciente
- Políticas públicas e diretrizes

Construindo Módulos

Equipes de pesquisa baseadas em universidades ou em organizações não governamentais sem fins lucrativos, desenvolvem a pesquisa baseada em entrevistas sobre a experiência de adoecimento e tratamento.

Cada seção ou módulo do site inclui 40-50 entrevistas (coletadas em vários locais do país), que após análise temática de conteúdo ilustrará as principais conclusões através de vídeos ou áudios das entrevistas. Completam o módulo comentários e informações contextuais sobre o problema de saúde.

Os sites permitem livre acesso a todo seu conteúdo - o website inglês foi premiado - e são amplamente utilizados por pacientes, familiares, profissionais de saúde em formação, bem como professores e pesquisadores voltados para melhorias na assistência à saúde.


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Breast Cancer in Women

For this module, we interviewed 35 women across Canada to hear about their experiences with breast cancer. They told us about their experiences including the good moments along with the challenges they encountered. Find out what women said about issues such as diagnosis, family and friends, and body image. We invite you to click on any of the links below to see, hear and read about their experiences. We hope you find the information helpful.


Introduction by Donna Stern




1. Diagnosis and Illness Pathway





2. Understanding Diagnosis and Trustworthy Information



3. Treatment Pathways





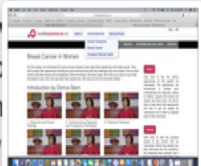


[Topics](#)

Click here to find the various experiences of the people we interviewed. The experiences are summarized in themes such as understanding the diagnosis, talking to children, support from family and friends, and many more. You will be able to read about their experiences and also to see the people we interviewed and to listen to selected parts of their interviews.

[People](#)

Click here to read the personal stories of the women that we interviewed. Where they explain how they discovered the first symptom, the treatments they received, how it had an impact on their lives, and




Austrália

research.healthtalkaustralia.org

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Our Members – DIPEX International Traumatic Brain Injury in Veterans (Coming Soon) – healthexperiencesusa.org Overview | healthtalkaustralia.org



Healthtalk
Australia



Emotional experiences of early parenthoodThe lived experience of ageingMental health: Carers' experiencesMental health and Supported Decision Making

Search

Talking pointsPeople's profilesResources and informationCredits

Overview

> Conception and pregnancy (6)

> Labour and birth (5)

> Early parenthood (6)

> Perinatal depression and anxiety (10)

> Relationships (4)

> Messages to others (2)

Overview

Welcome to the Emotional Experiences of Early Parenthood in Australian Families project.

Here, you can find out about people's emotional experiences of becoming a parent by seeing and hearing 45 parents living in Australia share their personal stories on film and audio-recording.

Our researchers travelled around Victoria and New South Wales to talk to 36 mothers and 9 fathers from a range of backgrounds and family arrangements. Find out what parents said about their experiences of conceiving, IVF, miscarriage, surrogacy, adoption, pregnancy, labour and birth, perinatal depression, life in early parenthood, relationships after becoming a parent, balancing parenthood with paid work, and advice to expecting and new parents as well as health professionals – to mention just some of the many topics covered! We hope you find the information helpful and reassuring.

You can start by watching an introduction from Monica Dux (social commentator, author of *Things I Didn't Expect (When I was Expecting)*, and editor of *Mothermorphosis*), and a preview of some of the clips below. You can also go straight to the 'Talking Points' on the left, or explore 'People's Profiles' above to learn more about the parents we talked to. (You may also be interested in our partner sites on [pregnancy and children](#) or [mental health](#).)

We welcome feedback from visitors to this site and are keen to hear your views. The [feedback survey](#) will take five minutes of your time to answer six short questions about your experience with this website.

An introduction by Monica Dux

Introduction to Early Parenthood by Monica Dux

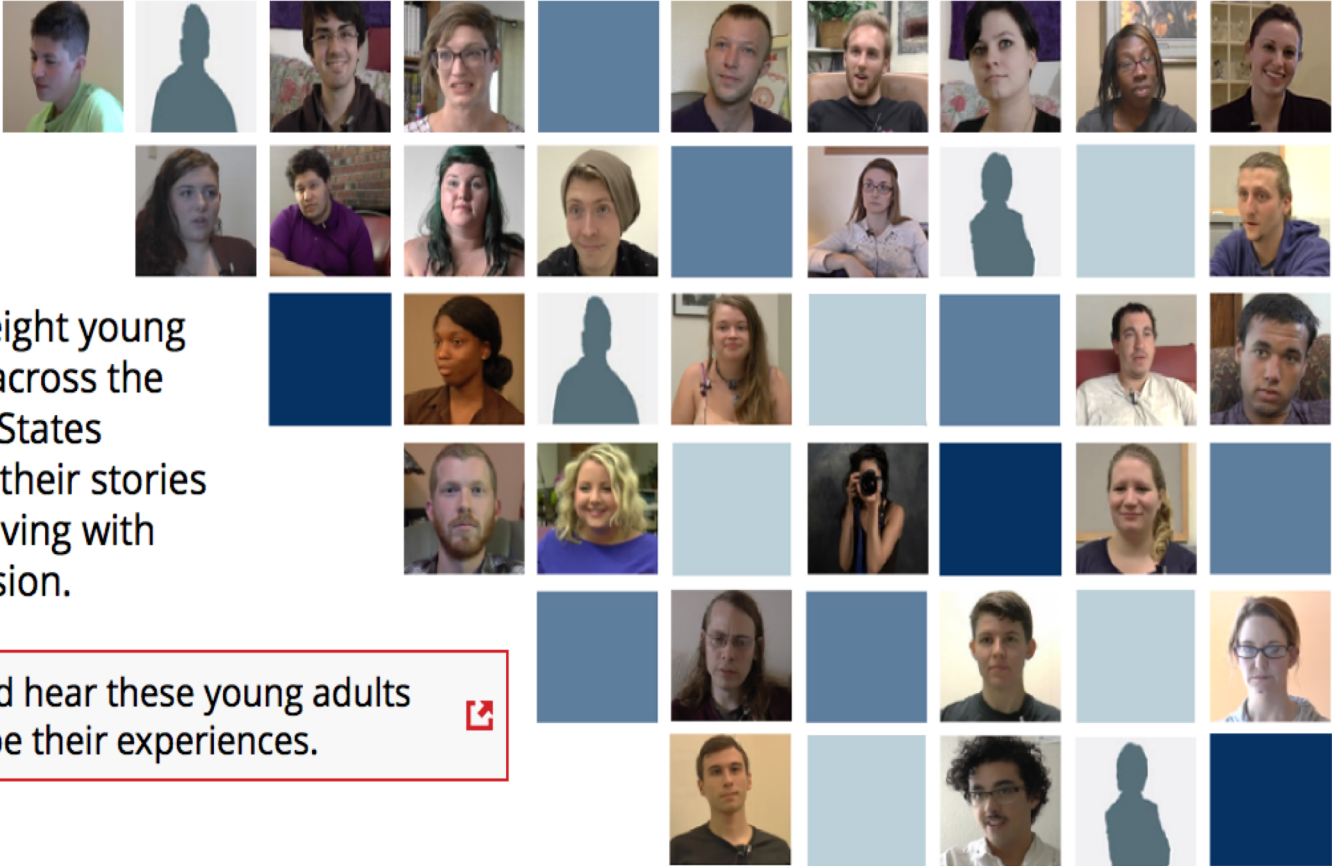


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Our Members - DIPEX International X Depression in Young Adults - healthexperiencesusa.org +

Depression in Young Adults



Thirty-eight young adults across the United States shared their stories about living with depression.

See and hear these young adults describe their experiences. 

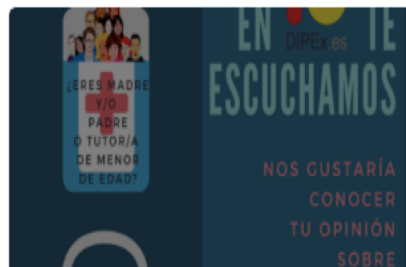
This module organizes clips from peoples' stories to illustrate:

- How depression feels
- Living with depression
- Coming to terms with depression
- Self-care strategies
- Seeking help and support
- Messages to others

Espanha

A close-up photograph of a hand holding a single, large, lustrous pearl between the thumb and index finger. The background is a clear, bright blue sky.

NARRATIVAS DE SALUD Y ENFERMEDAD EN PRIMERA PERSONA



EXPERIENCIAS SOBRE LA DIABETES
TIPO II



EXPERIENCIAS EN CUIDADOS