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Roadshow on Cancer and Chronic Diseases

21 October 2021

14:00-15:30 CEST / 13:00-14:30 BST

SAVE THE DATE

Panellists

Alle Bloom

UK Data Service

Beate Lichtwardt

Gry Henriksen

Norwegian Centre for Research Data

Patty Doran

University of Manchester

Nasir Raja

Danielle Freitas Gomes

Karen Dennison

University College London

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CESSDA is an ESFRI (European Strategy Forum on Research Infrastructures) Landmark. CESSDA is an ERIC (European Research Infrastructure Consortium), a European legal entity.

Agenda

1. Introduction, CESSDA® & Trust-IT
2. CESSDA Data Catalogue® - Discovery at national and European levels, **Alle Bloom, UK Data Service**
3. Resilience and living well beyond cancer: the relationship between emotional support and quality of life, **Patty Doran, University of Manchester**
4. Store and Protect with the CESSDA Data Management Guide®, **Gry-Hege Henriksen, Norwegian Centre for Research Data (NSD)**
5. Use case on Center for Longitudinal Studies - how to store and how to protect, **Danielle Freitas Gomes, Karen Dennison and Nasir Rajah, University College London**
6. Use case on The Five Safes framework for accessing sensitive data via the SecureLab at UK Data Service, **Beate Lichtwardt, UK Data Service**
7. Interactive Discussion - Connecting Researchers with CESSDA Service Providers to boost Societal Impact on Cancer and Major Chronic Diseases
8. Wrap up, CESSDA® & Trust-IT

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cessda Roadshow Series 2021

30 September
8-14-21-28 October

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CESSDA is an ESFRI (European Strategy Forum on Research Infrastructures) Landmark. CESSDA is an ERIC (European Research Infrastructure Consortium), a European legal entity.

Roadshow Synergies

CESSDA SERVICE PROVIDERS

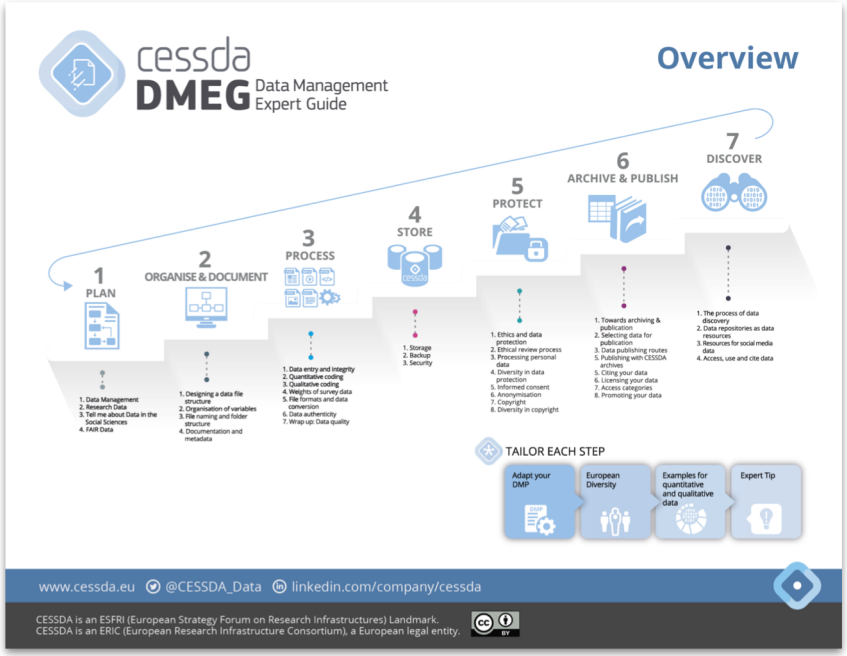
- APIS – Arquivo Português de Informação Social
- AUSSDA – Austrian Social Science Data Archive
- DANS – Data Archiving and Networked Services
- EKKE – Ethniko Kentro Koinonikon Ereunon
- Finnish Social Science Data Archive
- gesis – Leibniz Institute for the Social Sciences
- NSD – Norsk Senter for Forskningsdata
- UK Data Service
- SciencesPo

SYNERGIES WITH

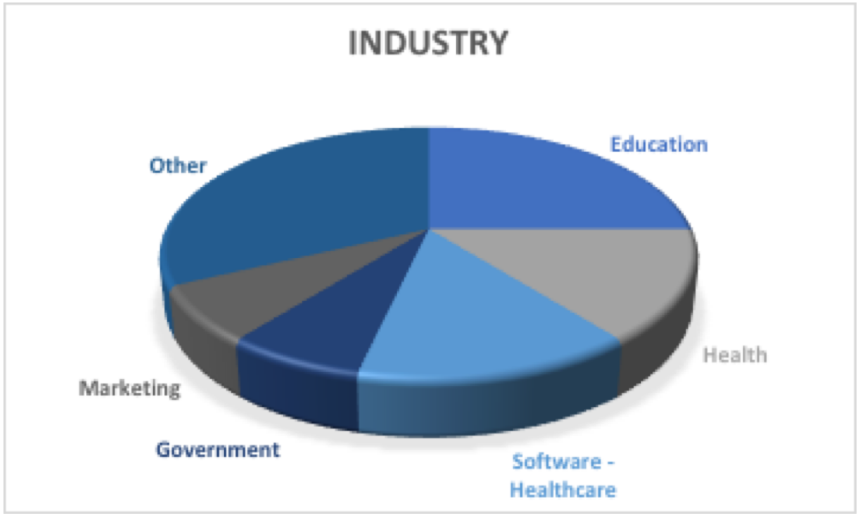
- eurodoc – The European Council of Doctoral Candidates and Junior Researchers
- HumMingBird
- Invorenew Coe
- MiCREATE
- SSHOC

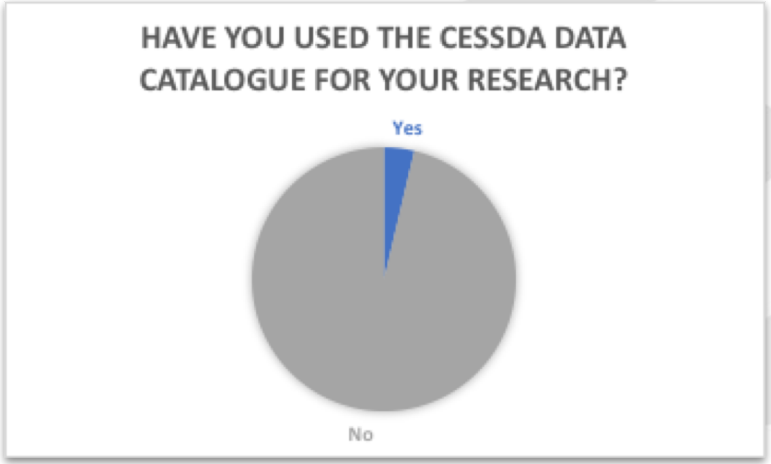
CESSDA Data Catalogue

Data Management Expert Guide



About you





While diving deep into the CESSDA Data Catalogue for discovery, we are very interested in learning about your user stories!

Got 3 minutes? We'd love your input!

Take our data users' survey by clicking the link in the chat! Or directly: https://www.surveymonkey.de/r/KGVN8S5

To enter the raffle for a free Audible audiobook, type a random FOUR DIGIT NUMBER in the space provided. The winner will be announced in the chat at the end of the webinar.

The survey data collected by CESSDA will improve CDC user experience. IP addresses are NOT collected. Emails given as part of the qualitative component will be deleted upon completion of the interview, in compliance with GDPR requirements.

CESSDA™ Data Catalogue - Discovery at national and European levels

CESSDA Roadshow: Cancer and Chronic Disease

Alle Bloom, UK Data Service

21st October 2021

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Steps in Data Discovery

Source: Gregory, et al., 2018b, CESSDA Training Team (2017 - 2020). *CESSDA Data Management Expert Guide.*
Bergen, Norway: CESSDA ERIC. Retrieved from https://www.cessda.eu/DMGuide

Places to find data – Data Resources

- Search engines
- Data lists/hubs
- Registers of data repositories
- Data journals
- Data catalogues

Source: CESSDA Training Team (2017 - 2020). *CESSDA Data Management Expert Guide.* Bergen, Norway: CESSDA ERIC. Retrieved from https://www.cessda.eu/DMGuide

CESSDA Data Catalogue (CDC)

The types of data found in the CDC include:

- Cross-national
- Country/nation - specific
- Labour force surveys
- Household panel surveys
- General social surveys

- Contains the metadata of all the data in the holdings of CESSDA's service providers
- Details of over 30,000 data collections are listed

Examples of available Cancer and Chronic diseases data

- Multiple countries or the whole of Europe (cross-national)
- Individual countries/areas

ECIS - European Cancer Information System

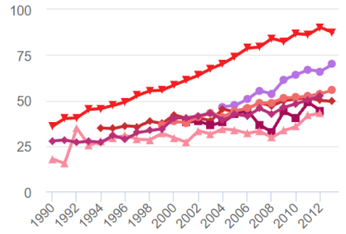
- EU27 and some non-EU countries
- Incidence and mortality for 2020 and historically
- Filters can be applied
- Maps and trends over time
- Allows for comparisons

Explore the data

Incidence and mortality estimates 2020

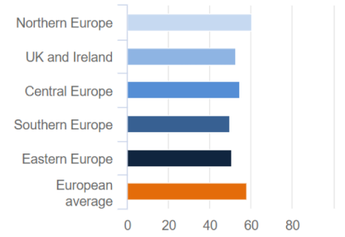
National estimates of cancer incidence and mortality in 2020, for the major cancer sites in European countries.

Non EU-27 countries have now been included



Incidence and mortality historical data

Incidence and mortality statistics over time by cancer site and demographic variables, in European cancer registration areas.



Survival estimates

Estimated indicators of survival, by cancer sites and sex, across European countries and regions.

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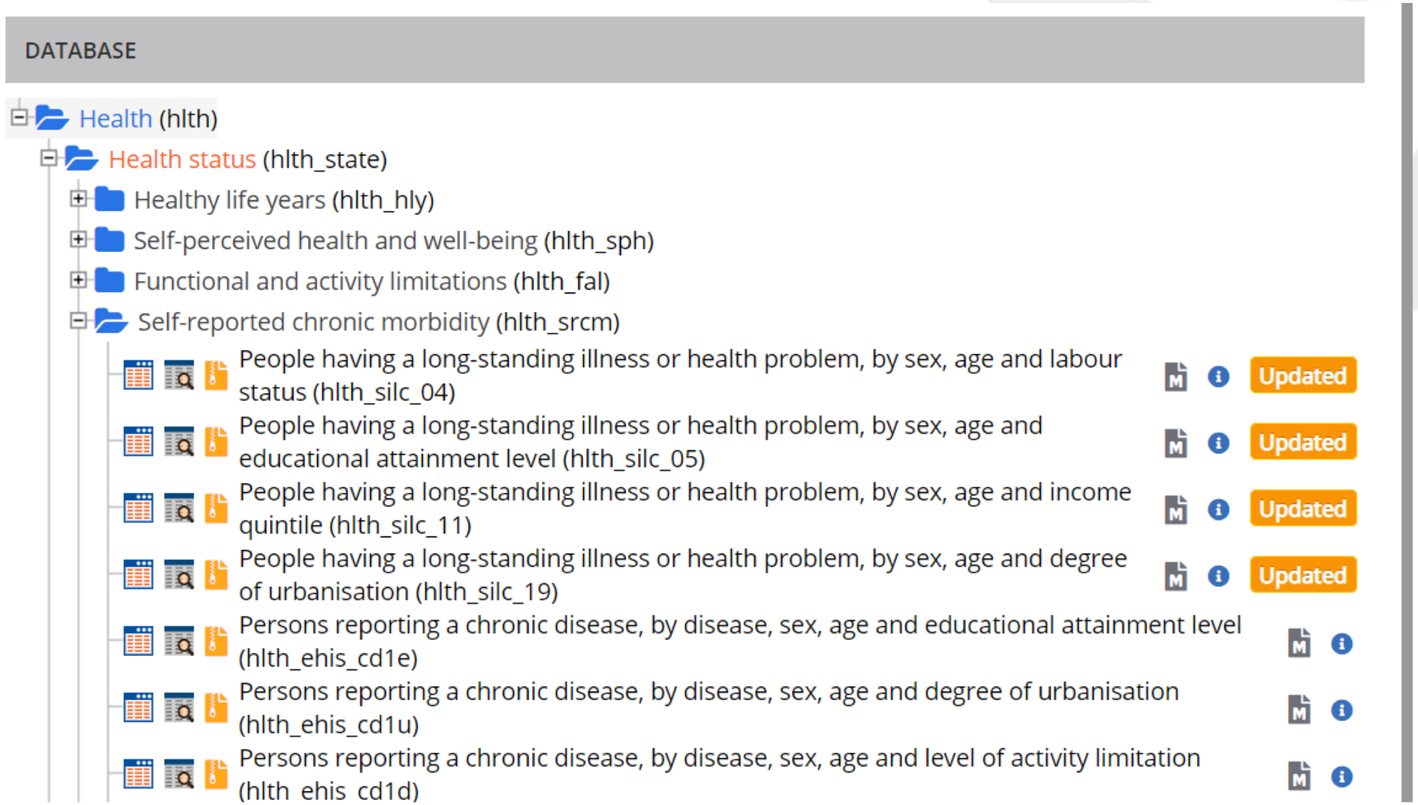
Eurostat – Europe-wide statistics

- data on long-standing illness or health problems by sex, age, labour status, urbanisation of area, educational attainment, activity limitation etc.
- Visualisations and graphs can be created
- Can be downloaded in multiple formats



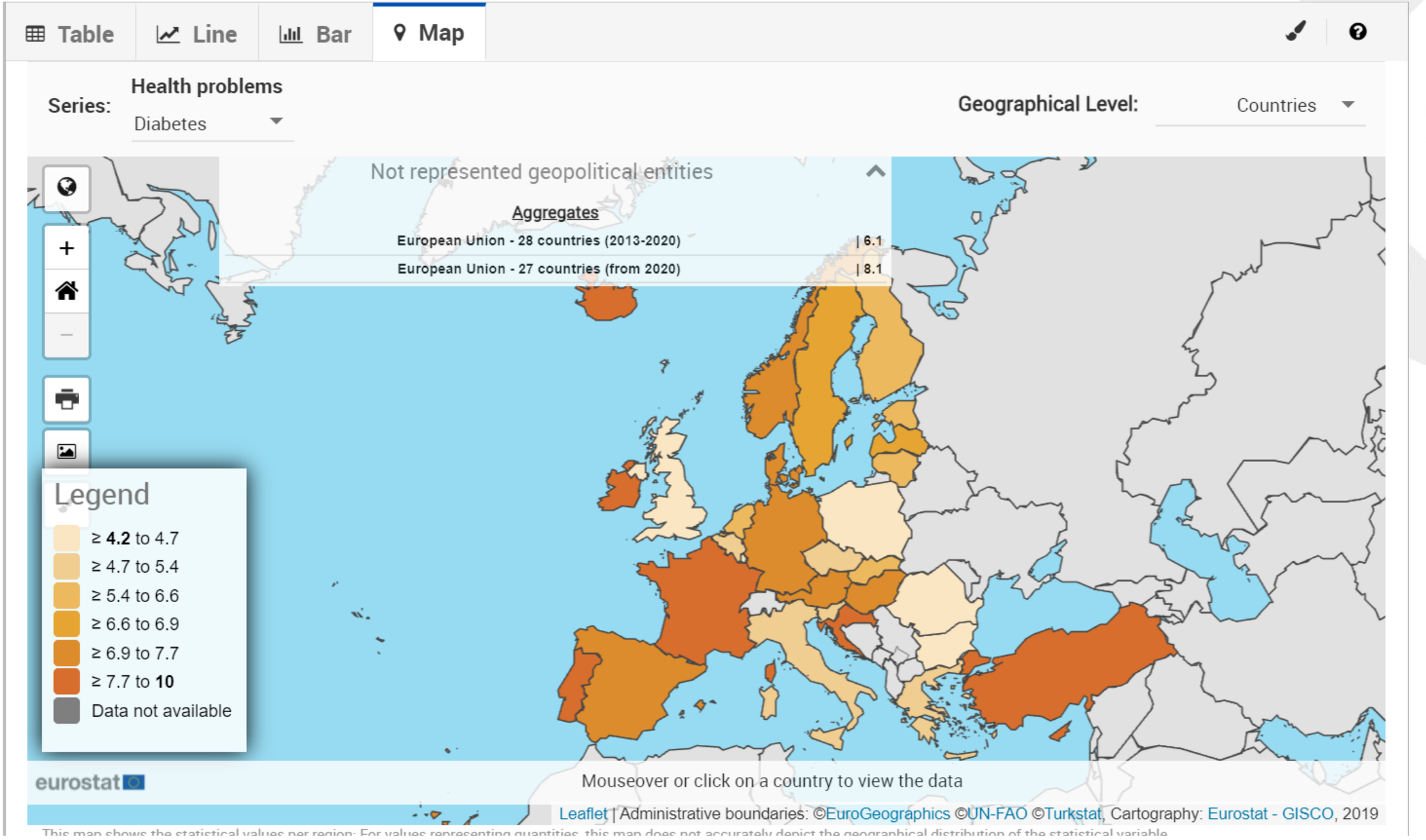


Table
Line
Bar
Map
Series:
Health problems
Diabetes
Geographical Level:
Countries
Not represented geopolitical entities
Aggregates
European Union - 28 countries (2013-2020) | 6.1
European Union - 27 countries (from 2020) | 8.1
Legend
≥ 4.2 to 4.7
≥ 4.7 to 5.4
≥ 5.4 to 6.6
≥ 6.6 to 6.9
≥ 6.9 to 7.7
≥ 7.7 to 10
Data not available
eurostat
Mouseover or click on a country to view the data
Leaflet | Administrative boundaries: ©EuroGeographics ©UN-FAO ©Turkstat, Cartography: Eurostat - GISCO, 2019
This map shows the statistical values per region: For values representing quantities, this map does not accurately depict the geographical distribution of the statistical variable

Health Care in Norway for People with Chronic Illnesses – Survey data

Quality, Accessibility and Coordination of Health Care in Norway for People with Chronic Illnesses - Seen From the Users Point of View, 2013. Lian, O. S. (2018).

- Cross-sectional postal survey
- April and May 2013
- Designed to gain knowledge about how those with chronic illnesses (in particular ME and Coeliac Disease) experience the quality, accessibility and coordination of primary and secondary health care in the Norwegian National Health System.
- International collaboration with three countries with similar health care systems.
- Metadata and terms of access can be found in CESSDA Data Catalogue.

Cancer Research UK Cancer Awareness Measures, 2019 – Survey data

- Repeated cross-sectional, web based survey
- Multiple waves of survey available
- Co-ordinated by Cancer Research UK
- Cancer Awareness Measures to assess:
  - Public awareness of types, symptoms, risk factors and screening programmes
  - Reasons patients delay in seeking treatment
  - The impact of messaging campaigns
- Metadata available through the CDC

CANCER RESEARCH UK

CESSDA Data Catalogue – Demonstration

MANCHESTER 1824
The University of Manchester
Institute for Collaborative
Research on Ageing

The Manchester Urban Ageing Research Group

Resilience and living well beyond cancer

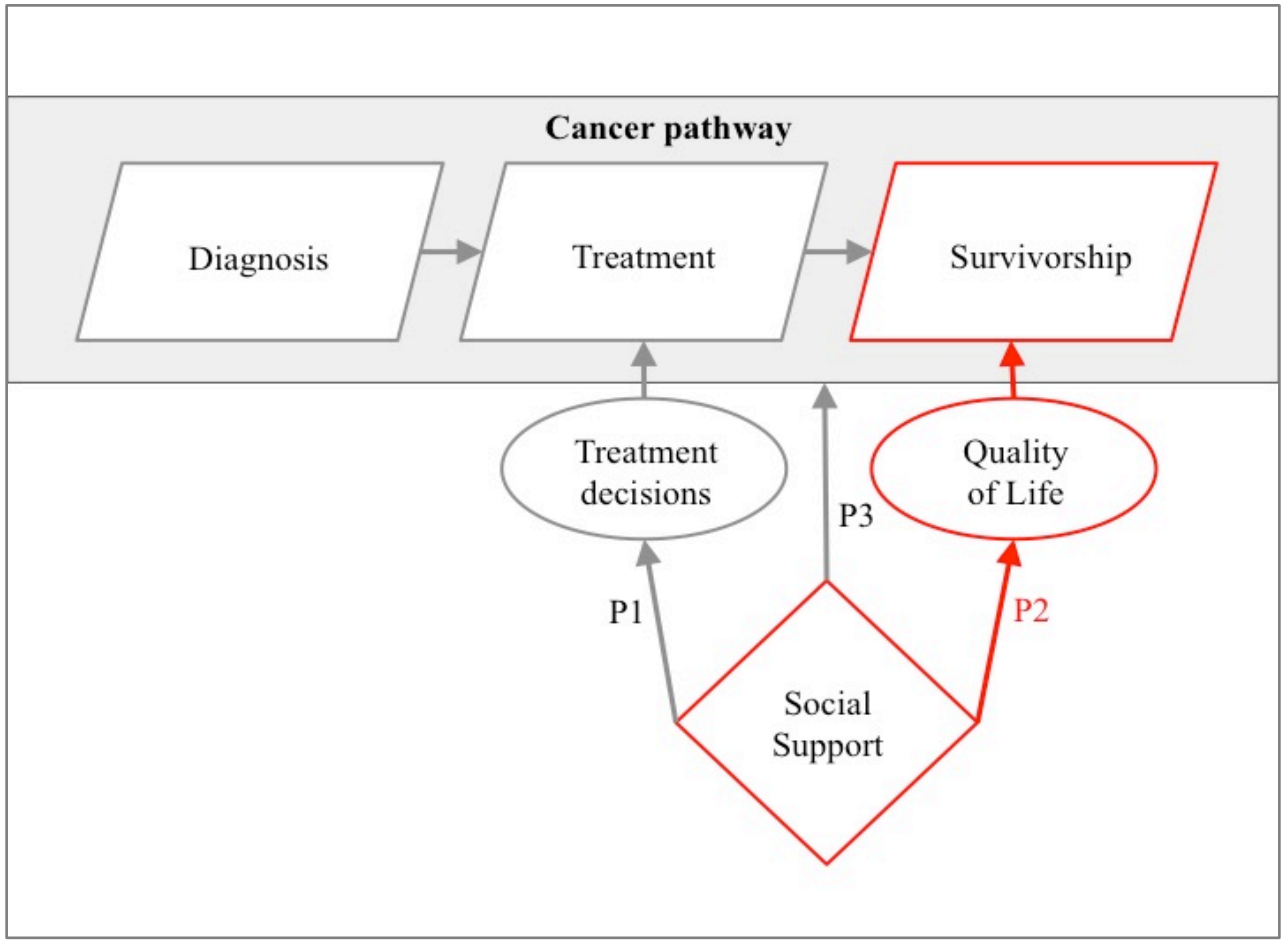
The relationship between emotional support and quality of life

Presented by Dr. Patty Doran

Aim

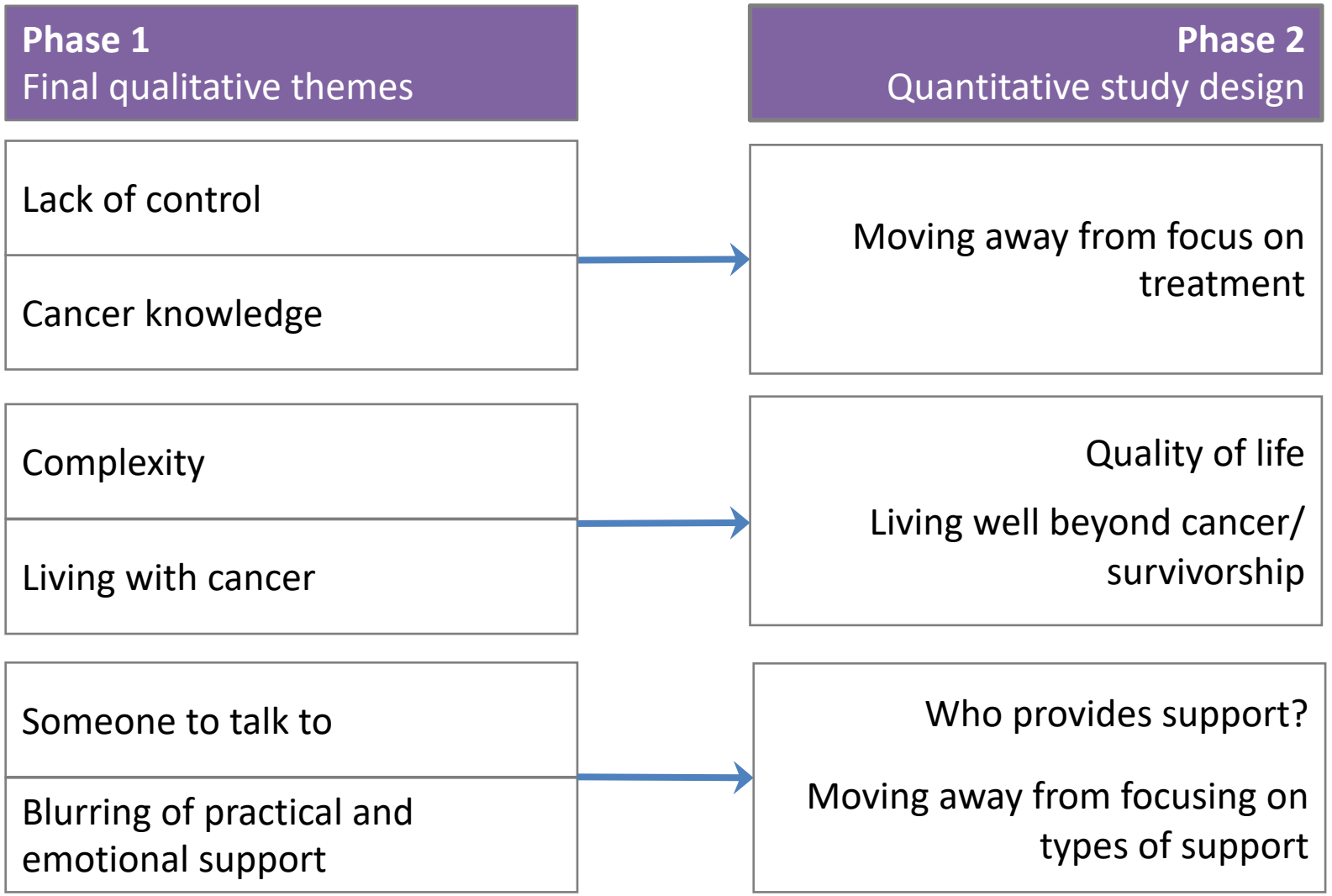
To investigate the influence of emotional support on the quality of life of older cancer survivors.

Social support along the cancer pathway: older people's experiences



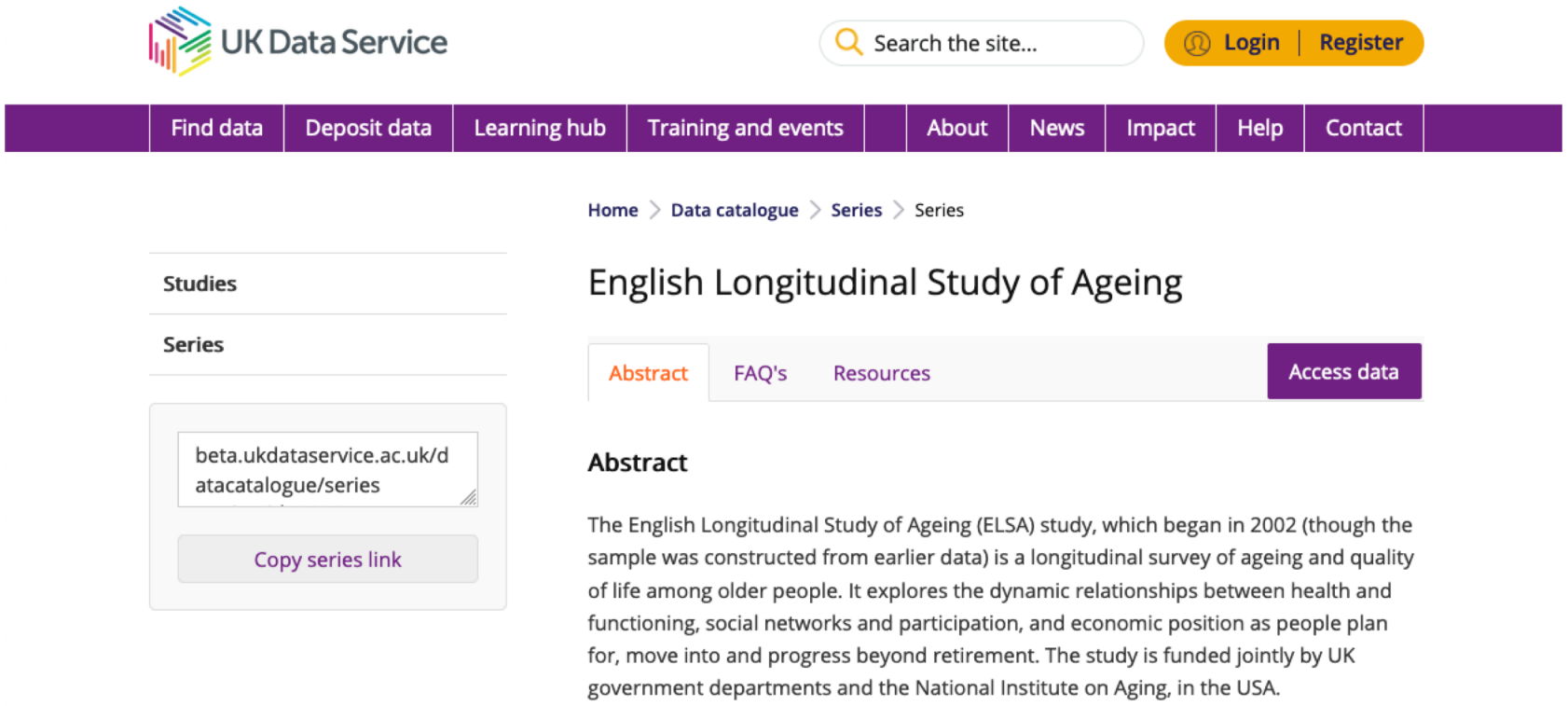
PhD Conceptual Framework: Phase 2, Quantitative – *Living Well Beyond Cancer Study*

Exploratory mixed-methods

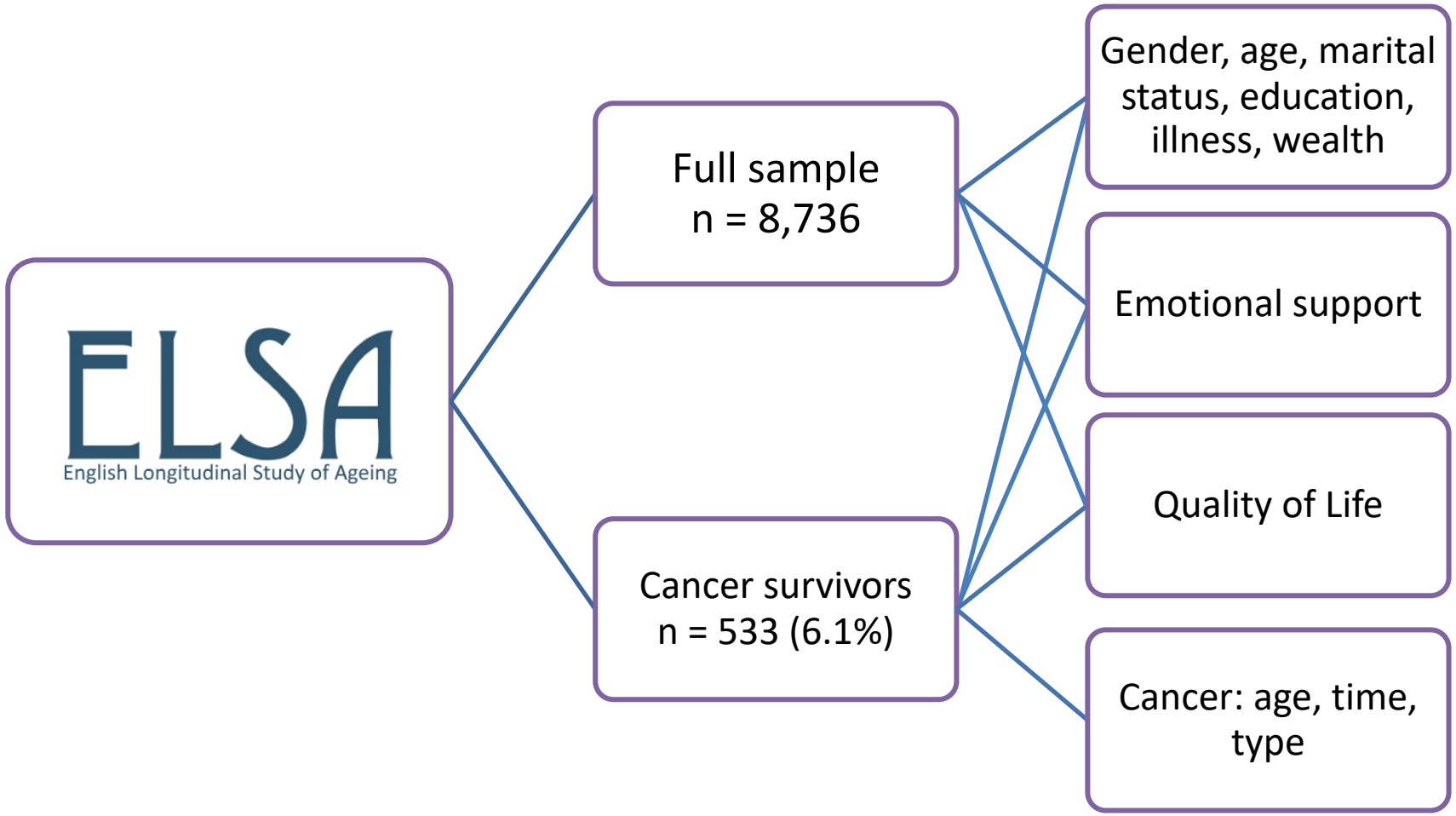


English Longitudinal Study of Ageing

Longitudinal cohort study of people aged 50+ in England

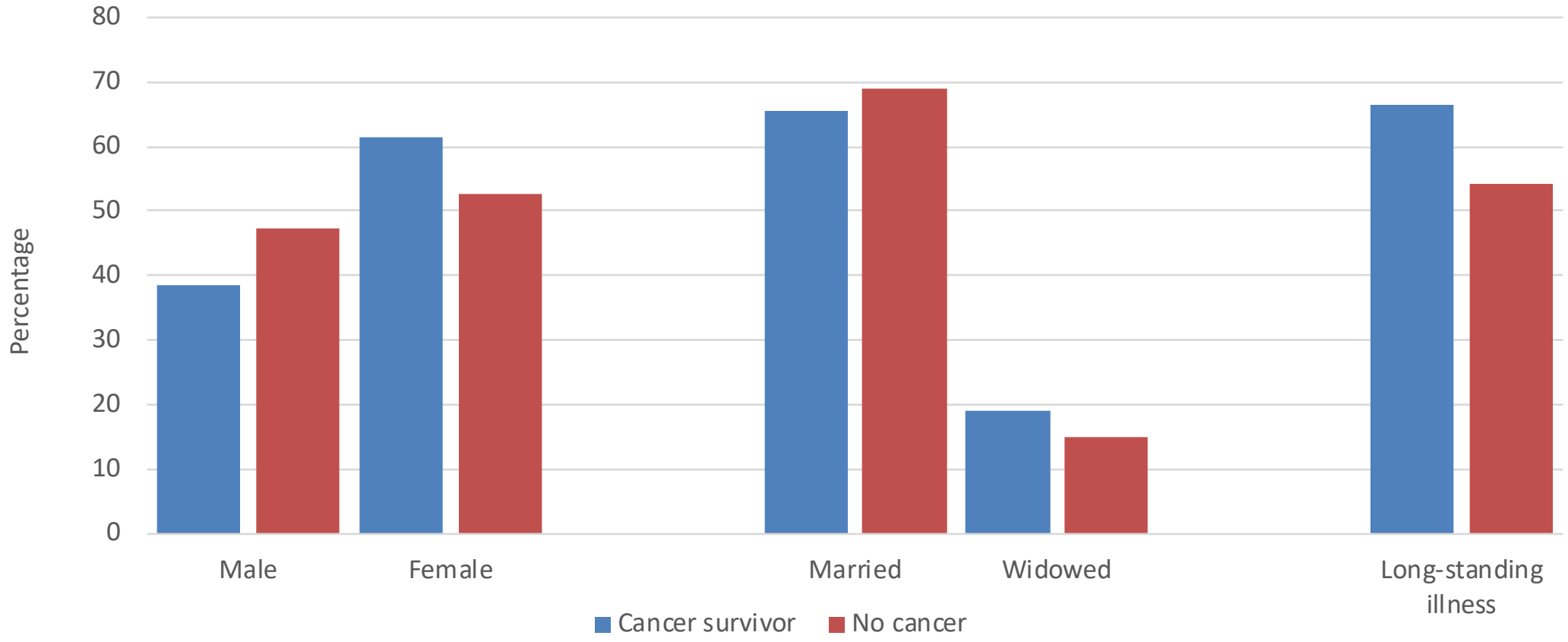


Methods


ELSA
English Longitudinal Study of Ageing
Full sample
n = 8,736
Cancer survivors
n = 533 (6.1%)
Gender, age, marital status, education, illness, wealth
Emotional support
Quality of Life
Cancer: age, time, type

Sample Descriptives

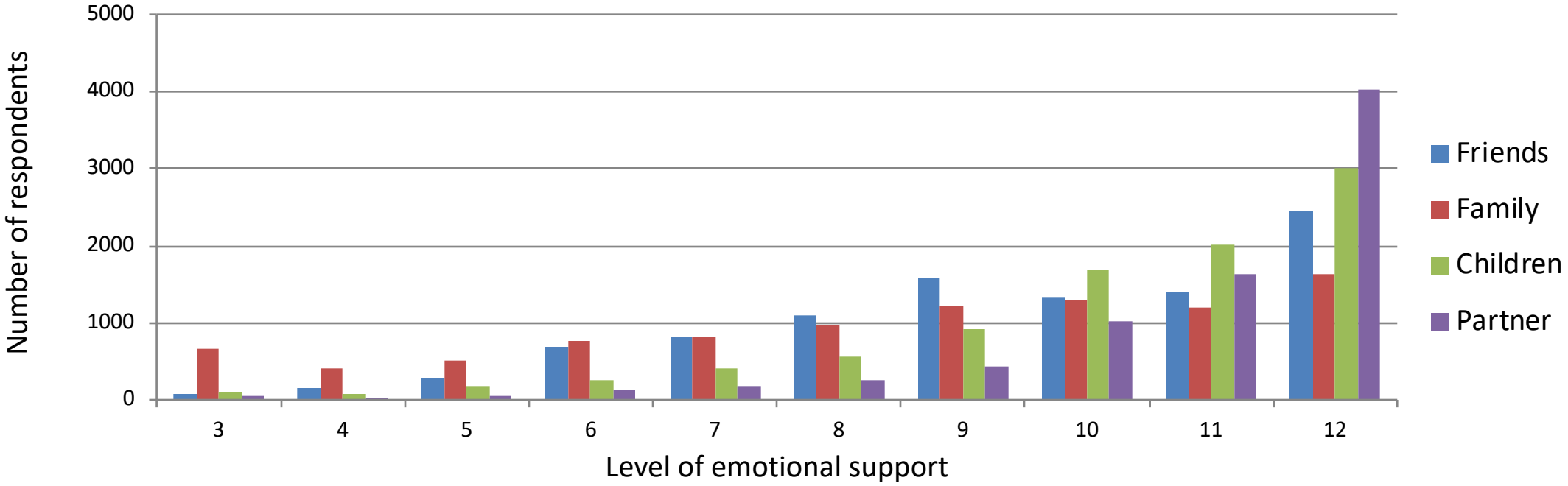
Significant differences between cancer survivors and older people without cancer in relation to gender, marital status and long-standing illness:



Emotional support

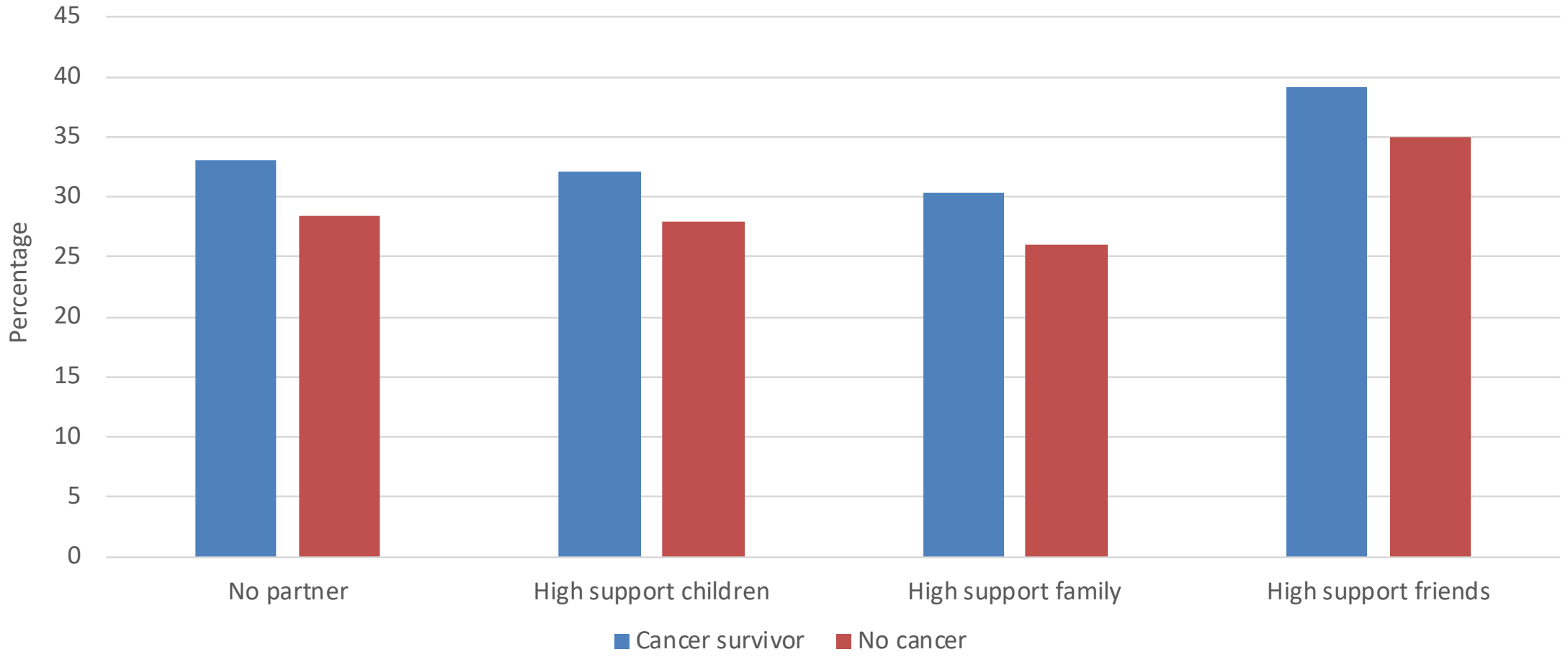
1. How much do they really understand the way you feel about things?
2. How much can you rely on them if you have a serious problem?
3. How much can you open up to them if you need to talk about your worries?

Distribution of combined emotional support scale across sources of support:



Sample descriptives: emotional support

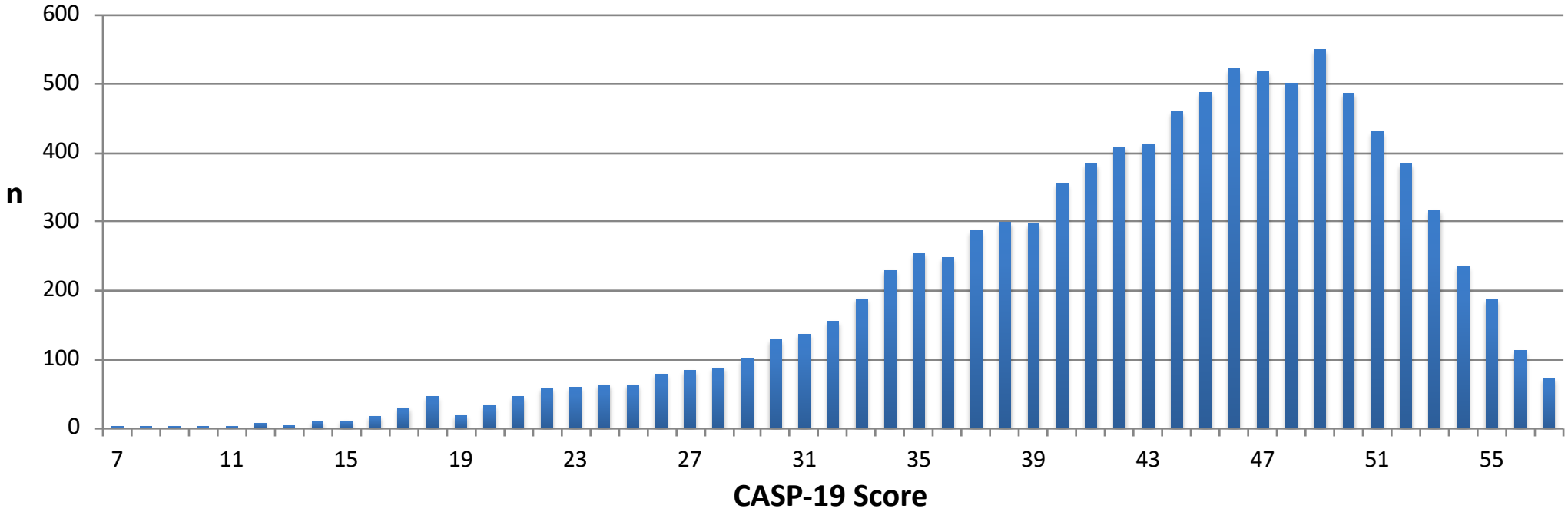
Significant differences between cancer survivors and older people without cancer in relation to emotional support:



Quality of life

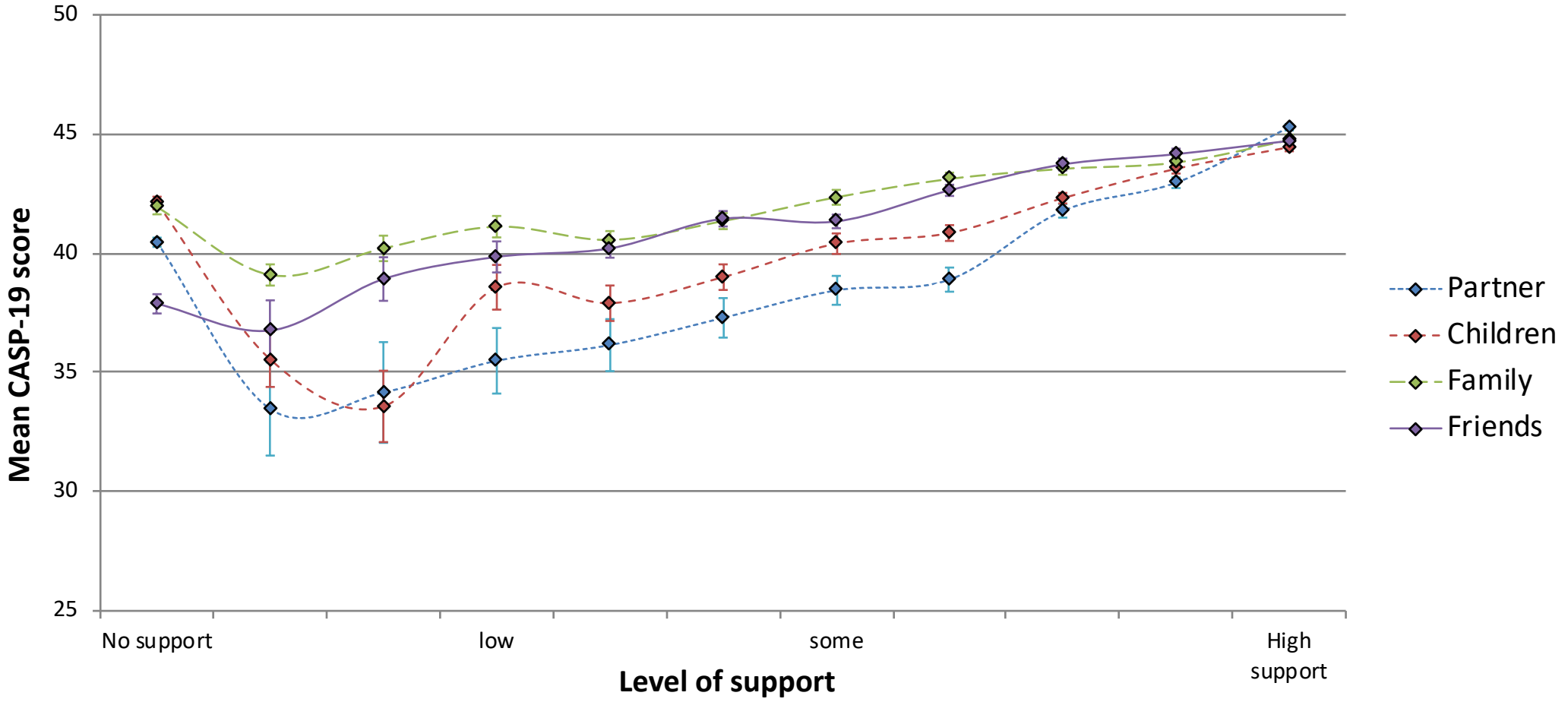
The CASP-19 QoL tool is a needs-based measure that covers four domains: Control, Autonomy, Self-realisation, and Pleasure (Hyde et al., 2003).

Distribution of combined CASP-19 score across sample:



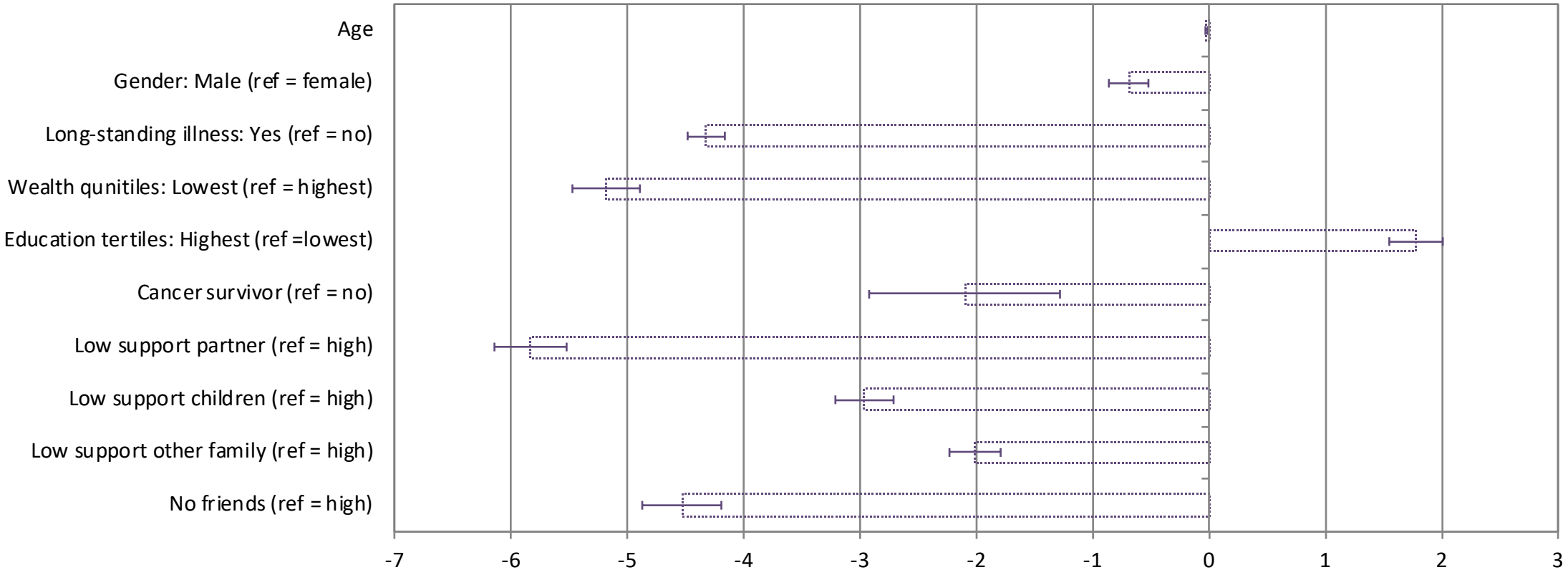
Quality of life and emotional support

Mean Quality of Life score by level of social support from partner, children, family and friends:



Regression results

Linear regression model of relationship between emotional support and quality of life with cancer as a binary variable (selected results):



Notes: All variables significant to p=0.01, except cancer survivor p=0.05; Constant B=53.64 (SE 0.66)

Discussion

- Positive relationship between emotional support and quality of life.
- Low (as opposed to no) emotional support was associated with the lowest levels of quality of life.
- The negative impact of having a cancer diagnosis added significantly to lower quality of life.

Limitations

- Small sub-set of cancer survivors in ELSA
- More women, higher mean age, more likely to be widowed and have a long-standing illness.
- Cancer variables limited
- Sources of support limited

Conclusions

- The relationship between emotional support and quality of life was similarly present for both cancer survivors and older people without cancer.
- However, low emotional support compounds with the independent detrimental effect on quality of life of being a cancer survivor.
- Low emotional support trend perhaps reflects complex situations.

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SAGE

Older People Living Well Beyond Cancer: The Relationship Between Emotional Support and Quality of Life

Patty Doran, MSc[1], Sorrel Burden, PhD[1], and Nick Shryane, PhD[1]

Abstract

Objective: To investigate the influence of emotional support on the quality of life (QoL) of older cancer survivors. **Method:** We use data from the English Longitudinal Study of Ageing to assess the relationship between perceived emotional support and QoL, comparing people who were cancer survivors ($n = 533$) to people without cancer ($n = 8{,}203$). **Results:** Most people reported high emotional support and had good QoL ($M = 42.57$, scale = 0-57). However, linear regression modeling showed cancer survivors had on average slightly lower QoL (–2.10 $SE = 0.82$). Those who reported having low support reported much poorer QoL; this relationship was similar for both cancer survivors and people without cancer. **Discussion:** The impact of low emotional support on QoL compounds with the independent detrimental effect of being a cancer survivor. Interventions that increase emotional support are likely to improve QoL for cancer survivors.

Aging and Health

Selected references

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The University of Manchester
Institute for Collaborative
Research on Ageing

Patty Doran
The Manchester Urban Ageing Research Group

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e: patty.doran@manchester.ac.uk
t: @Patty_NZ

The CESSDA Roadshow – Cancer and Chronic Disease

Store and Protect with the CESSDA Data Management Expert Guide®

Gry H. Henriksen/ NSD – Norwegian Centre for Research Data

21 October 2021

cessda.eu @CESSDA_Data

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DMEG - The Data Management Expert Guide

- Guide on Research Data Management (RDM)
- One central place for information on Research Data Management
- Created by CESSDA training team 2017 – 2020
- Free use: www.cessda.eu/dmeg

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DMEG follows the data lifecycle

DMEG follows the data lifecycle

Data storage

Where?

Data storage

Where?

Hard-drive?

Cloud Services?

Research Server?

Laptop?

Data storage

What about?

Backup?

Access restrictions?

Software malfunctions?

Data Integrity

Data Protection:
Legal and ethical obligations to participants

- Upholding Scientific Standards
- Compliance with the law
- Avoidance of social and personal harm

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Data Protection:
Ethical Review Process

- Ethics review by a Research Ethics Committee (REC)
- Ethical self-assessment
- Rules and guidelines will differ from country-to-country as well as from research funder to research funder

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Data protection:
General Data Protection Regulations, May 2018

- Personal data on EU citizens
- GDPR + National laws on data protection

Data protection:
General Data Protection Regulations, May 2018

- Personal data on EU citizens
- GDPR + National laws on data protection

Data protection:
Two approaches

- Not collect personal data
- Anonymisation

Data protection:
Two approaches

- Not collect personal data
- Anonymisation

TIP

A Data Management Plan
Useful tool to think ahead
Allows for easy project management
Clarifies needed budget
Makes data FAIRer
Shows accountability
DMP

Thank you for your attention

Gry H.Henriksen, NSD – Norwegian Centre for Research Data

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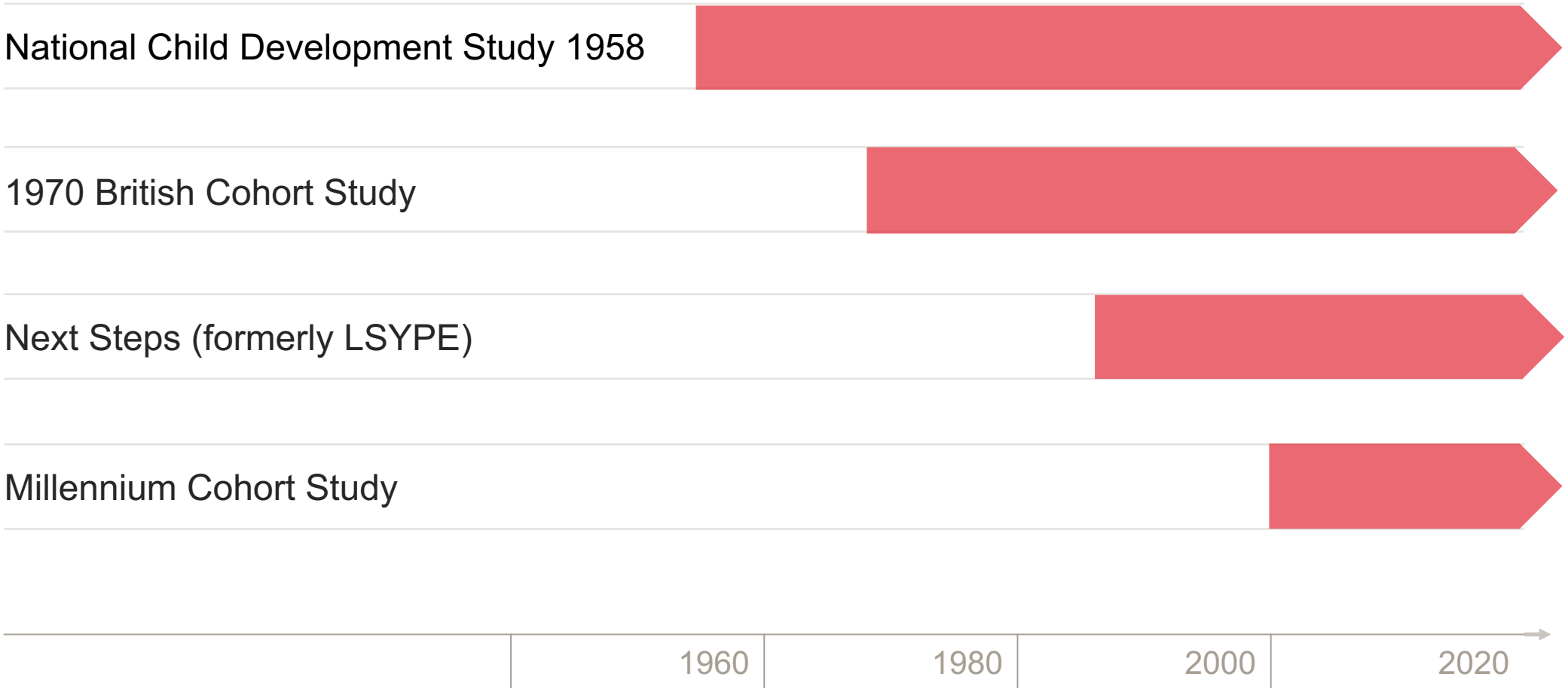
CENTRE FOR LONGITUDINAL STUDIES

CLS Studies Linkage to Health Data

Record Linkage Managers
Danielle Gomes
Karen Dennison

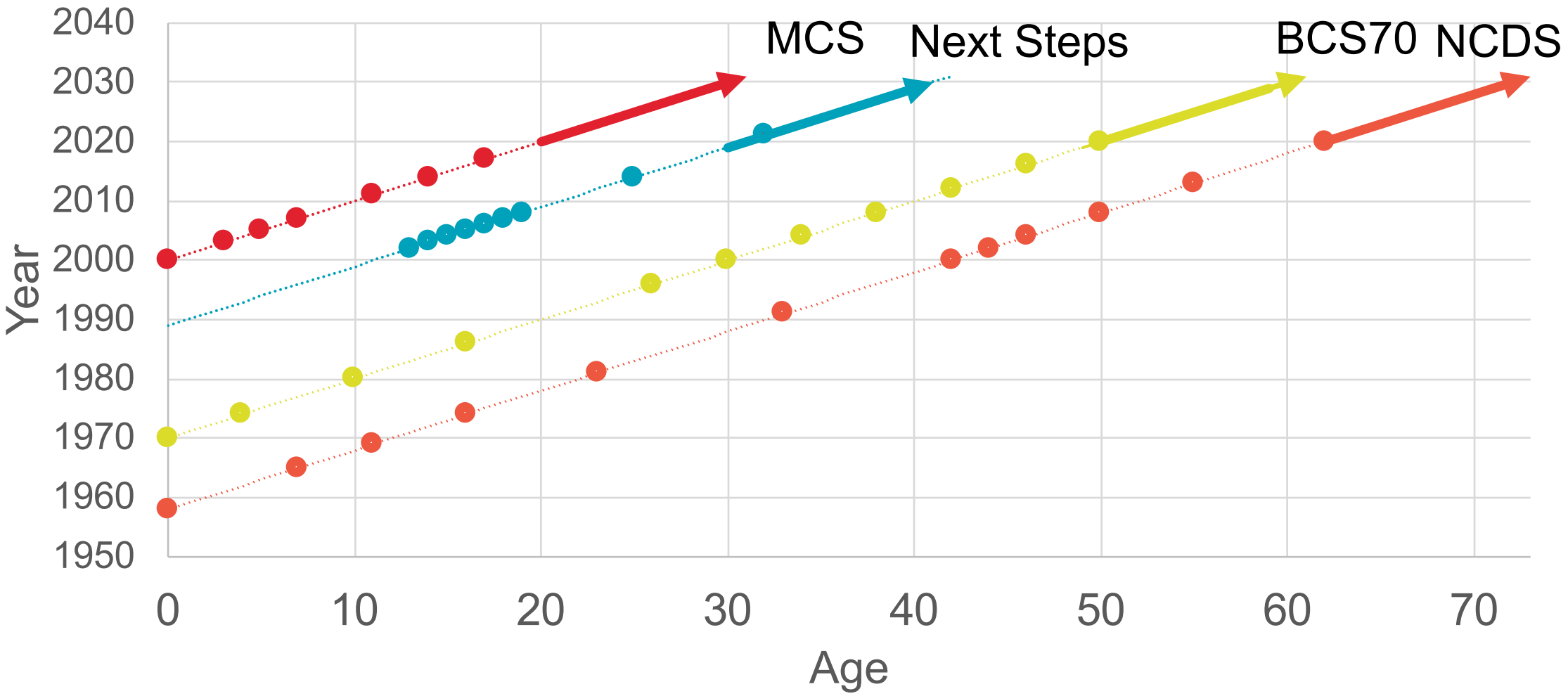
Centre for Longitudinal Studies: we follow people across life

CENTRE FOR LONGITUDINAL STUDIES



Study timelines

CENTRE FOR LONGITUDINAL STUDIES



Typical information covered

CENTRE FOR LONGITUDINAL STUDIES

Birth (excluding Next Steps)	School years	Adult
Household composition	Household composition	Household composition
Parental social class	Parental social class	Employment
Obstetric history	Parental employment	Social class
Smoking in pregnancy	Financial circumstances	Income
Pregnancy (problems, antenatal care)	Housing	Housing
Labour (length, pain relief, problems)	Health	Health (including biomarkers)
Birthweight, length	Cognitive tests	Well-being and mental health
	Emotions and behaviour	Health-related behaviour
	School	Training and qualifications
	Views and expectations	Basic skills
	Attainment	Cognitive tests
		Views and expectations

Data Linkage

CENTRE FOR LONGITUDINAL STUDIES

- CLS has a data linkage programme to link a range of administrative data to the survey data
- CLS creates a randomised study ID for each participant (CLS ID)
- CLS sends matching variables such as name, address, sex, Dob and the CLS ID to the data providers
- The data providers link the study's participants to the people in their database and extract the corresponding health records
- The data provider removes the identifiable information, except for the CLS ID and sends the research data back to CLS
- CLS has a separation in place, the team that handles the identifiable information have no access to the research data
- The data is returned to the Research Data team, who has no access to the identifiable data
- The research data team cleans the data and carries out disclosure control of the data before depositing it at the UKDS

Data storage

CENTRE FOR LONGITUDINAL STUDIES

- Data is stored at the UCL Data Safe Haven
- The UCL DSH is certified to ISO 27001
- Staff and researchers using UCL DSH complete annual training
- Data access is limited to those authorised to access it
- Access to the UCL DSH is via remote desktop and requires multi-factor authentication
- In addition to a strong password, each user has to use a six digit number generated by a smartphone app or physical token at each time
- Once inside the environment, robust access control ensures that users can only examine information that they are approved to use

What health data are available ?

CENTRE FOR LONGITUDINAL STUDIES

England (all studies)

- Inpatient care (including maternity data)
- Outpatient care
- Critical care
- Accident and Emergency

Wales (MCS)

- Deposited with SAIL Databank
- Range of health data –
  - Cancer
  - COVID
  - Critical care
  - Emergency Department
  - Maternity
  - Outpatient
  - Primary Care GP data

Scotland (NCDS, BCS70, MCS)

- Inpatient care
- Outpatient care
- Maternity records
- Prescribing information system
- Birth & neonatal records (MCS only)
- Child Health Records (MCS only)
- Immunisation (MCS only)

Data typically include

Diagnostic codes (ICD-10)
Operation Chapter (OPCS-4)
Indices of Multiple Deprivation
Administrative data e.g. Health Authority
Dates of admission, discharge etc

Negotiations with data controllers

CENTRE FOR LONGITUDINAL STUDIES

- Lengthy process, can be costly
- Liaise with your legal team
- Establish legal basis for processing
- Avoid GDPR consent as legal basis
- Consider a sub-licensing arrangement
- Fulfilment of data controller requirements:
    - Data minimization
    - Applicants demonstrate public benefit/health and social care benefit
    - Institutional responsibility
    - Right to audit
    - Data security

How are participants protected?

CENTRE FOR LONGITUDINAL STUDIES

- Linkage is conducted only for those participants who consented to health linkage.
- CLS keeps participants informed about the linkage program via mailing and on the study website.
- CLS has a separation system which keeps identifiable information separate from research/attribute information.
- All data made available for research is pseudonymised using the study ID.
- Researchers applying to access the data will need to complete the mandatory training before they are allowed to access the data.
- Data is only provided under controlled access via the UKDS Secure Lab.
- Researchers willing to access must make an application detailing the intended analysis.
- Researchers must usually specify the variables that they require for the project and will only be given access to a tailor-made subset as specified in their application
- The user and their organisation will be required to agree and sign the confidentiality terms stated in the Secure Access agreement. By signing this, the user agree to respect the privacy of the participant's data they will receive and are reminded of penalties they are likely to incur if they don't comply.
- Disclosure control is conducted before the researcher can publish their papers.

The importance of making this data available

- It is costly for each researcher to apply individually. By depositing it with the UKDS it is free at the point of use.
- Combined with the survey, this linked data has great potential to contribute to scientific research and as result improve the lives of people with specific health conditions.
- The linked data provides rich information about the individual's health and usage of NHS services, which is not yet available in all cohort studies.
- If the linked data is population representative, we will be able to leverage the rich nature of the birth cohort study for various pieces of research.
- Linked HES data can be used to predict non-response in the cohort studies (which is what CLS is currently doing).

CENTRE FOR LONGITUDINAL STUDIES

Any questions?

For further information:
clsrecordslinkage@ucl.ac.uk

UK Data Service

The Five Safes framework – remote access to sensitive data via the UKDS SecureLab

Beate Lichtwardt, UK Data Service

CESSDA Roadshow: Major Chronic Diseases and Cancer

21 October 2021

Economic and Social Research Council

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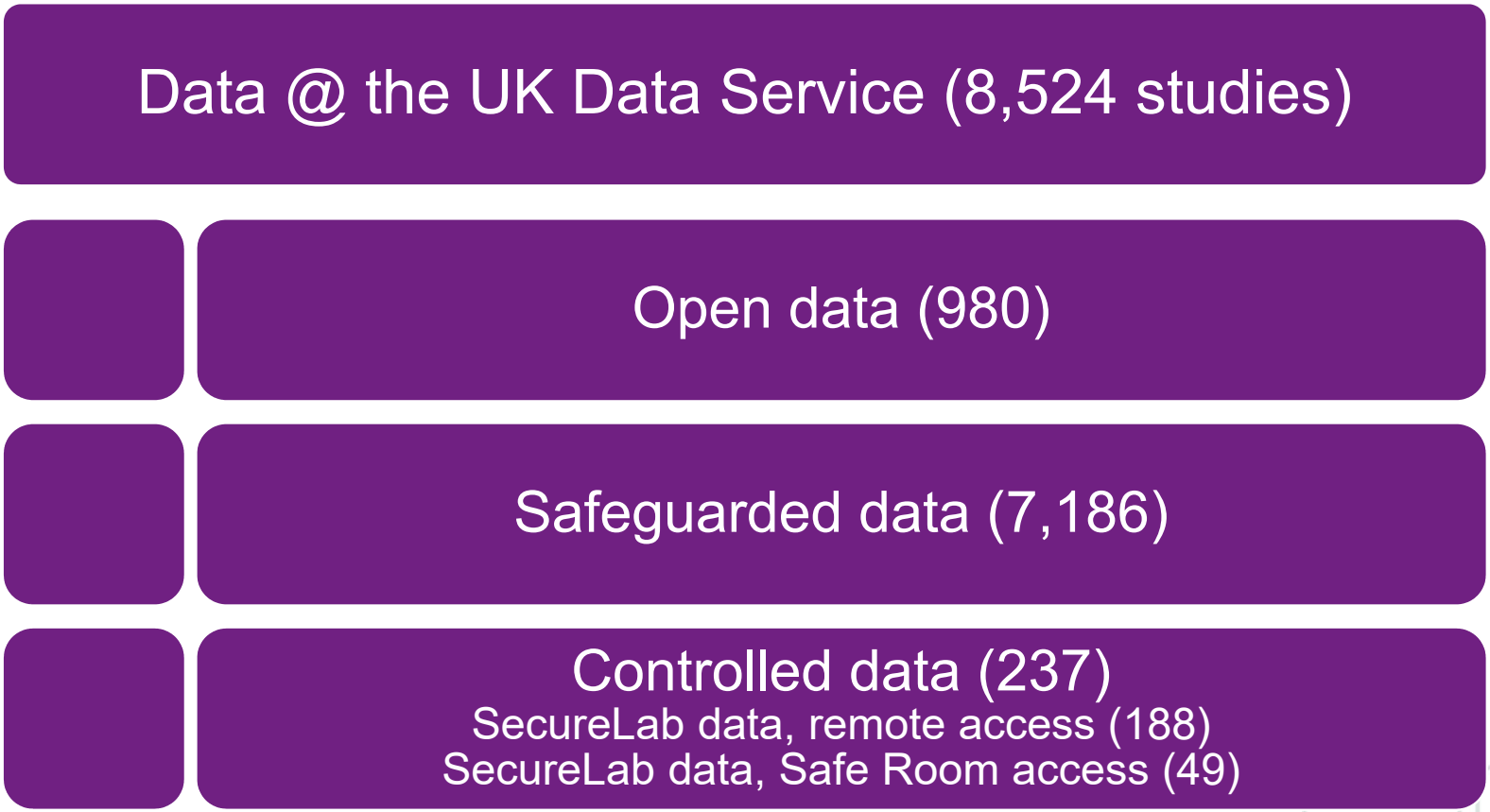
Roadmap

- Sensitive/ controlled data @ the UK Data Service
- The Five Safes – a framework for safe data access
- UKDS SecureLab – 10 years remote access to controlled data for research


Data @ the UK Data Service (8,524 studies)
Open data (980)
Safeguarded data (7,186)
Controlled data (237)
SecureLab data, remote access (188)
SecureLab data, Safe Room access (49)

Data @ the UK Data Service

UK Surveys	large-scale government funded surveys
Longitudinal	major UK surveys following individuals over time
International	multi-nation aggregate databanks (macro) and survey (micro) data
Qualitative	range of multimedia qualitative and mixed methods data
Census	Census data 1961 – 2011
Business	business microdata
Administrative	records for admin. data, for which ADRN has negotiated researcher access
Controlled International Microdata	IAB (Germany) CASD (France)

Our data collections by access level

Data access conditions	Access level
Open Licence	Open
End User Licence (EUL) [Authentication]	Safeguarded
Special Conditions (SC) [Authentication]	
Special Licence (SL) [Authentication, Accredited Researcher Status]	
SecureLab Data Access (remote) [Authentication, Accredited Researcher Status, Training + Test]	Controlled
SecureLab Data Safe Room Access (on-site) [Authentication, Accredited Researcher Status, Training + Test]	

The Government Statistical Service Policy for the release of social survey microdata ensures compliance with the
- Code of Practice for Official Statistics (CoP),
- Statistics and Registration Service Act (SRSA), 2007.

ons.gov.uk/methodology/methodologytopicsandstatisticalconcepts/disclosurecontrol/policyforsocialsurveymicrodata

Example - SecureLab MCS datasets

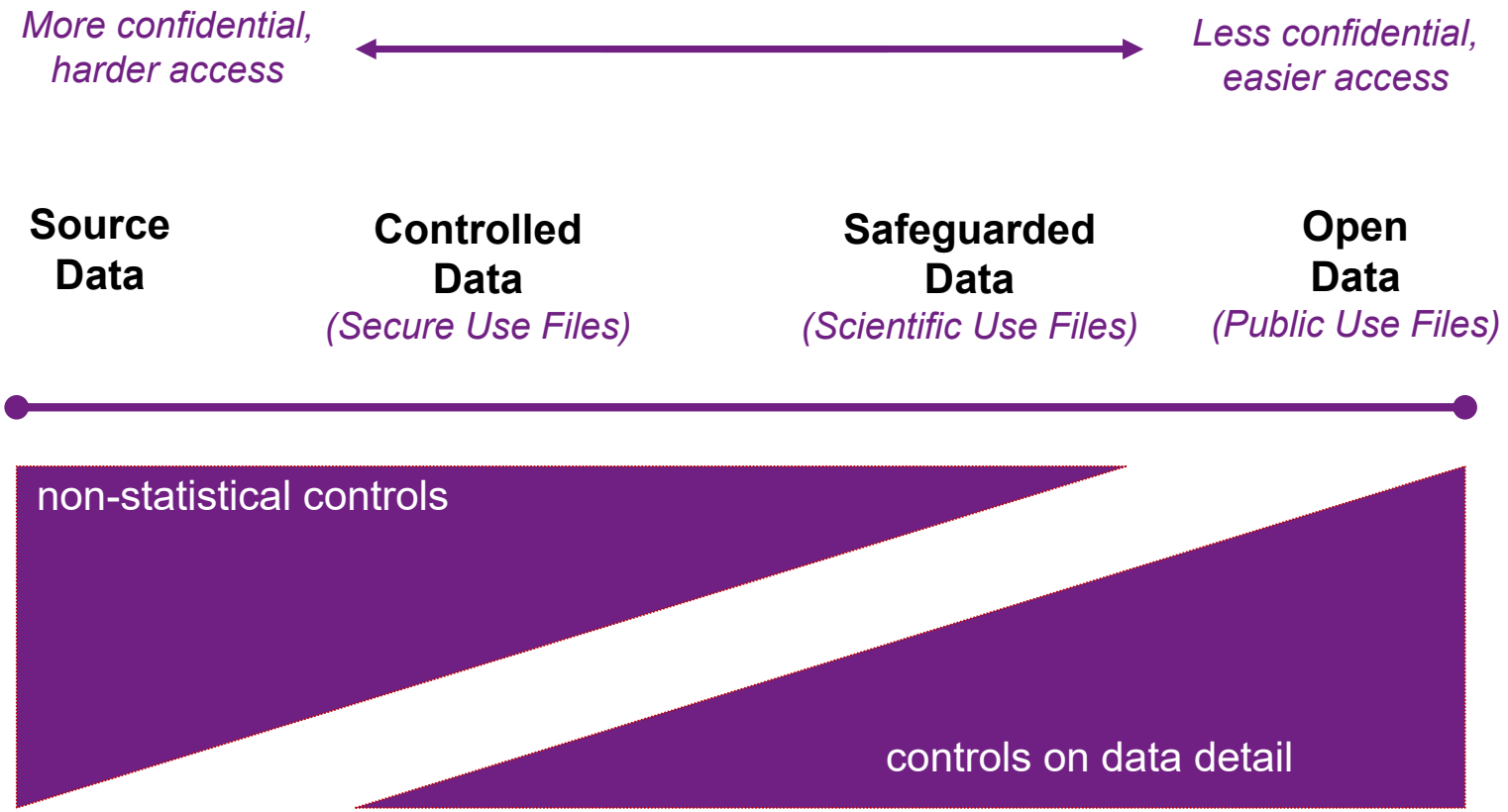
GN 33445

Millennium Cohort Study - Linked Administrative Data

SN	Study description	Explore online	Select
8785	Millennium Cohort Study: Age 5, Sweep 3, 2006: Foundation Stage Profile and Teacher Survey		Login
8714	Millennium Cohort Study: Linked Health Administrative Data (Scottish Medical Records), Outpatient Attendance, 2001-2015: Secure Access		Login
8713	Millennium Cohort Study: Linked Health Administrative Data (Scottish Medical Records), Inpatient and Day Care Attendance, 2000-2015: Secure Access		Login
8712	Millennium Cohort Study: Linked Health Administrative Data (Scottish Medical Records), Scottish Birth Records, 2000-2002: Secure Access		Login
8711	Millennium Cohort Study: Linked Health Administrative Data (Scottish Medical Records), Scottish Immunisation and Recall System, 2000-2015: Secure Access		Login
8710	Millennium Cohort Study: Linked Health Administrative Data (Scottish Medical Records), Prescribing Information System, 2009-2015: Secure Access		Login

https://beta.ukdataservice.ac.uk/datacatalogue/series/series?id=2000031#!/access-data

Managing data access nationally

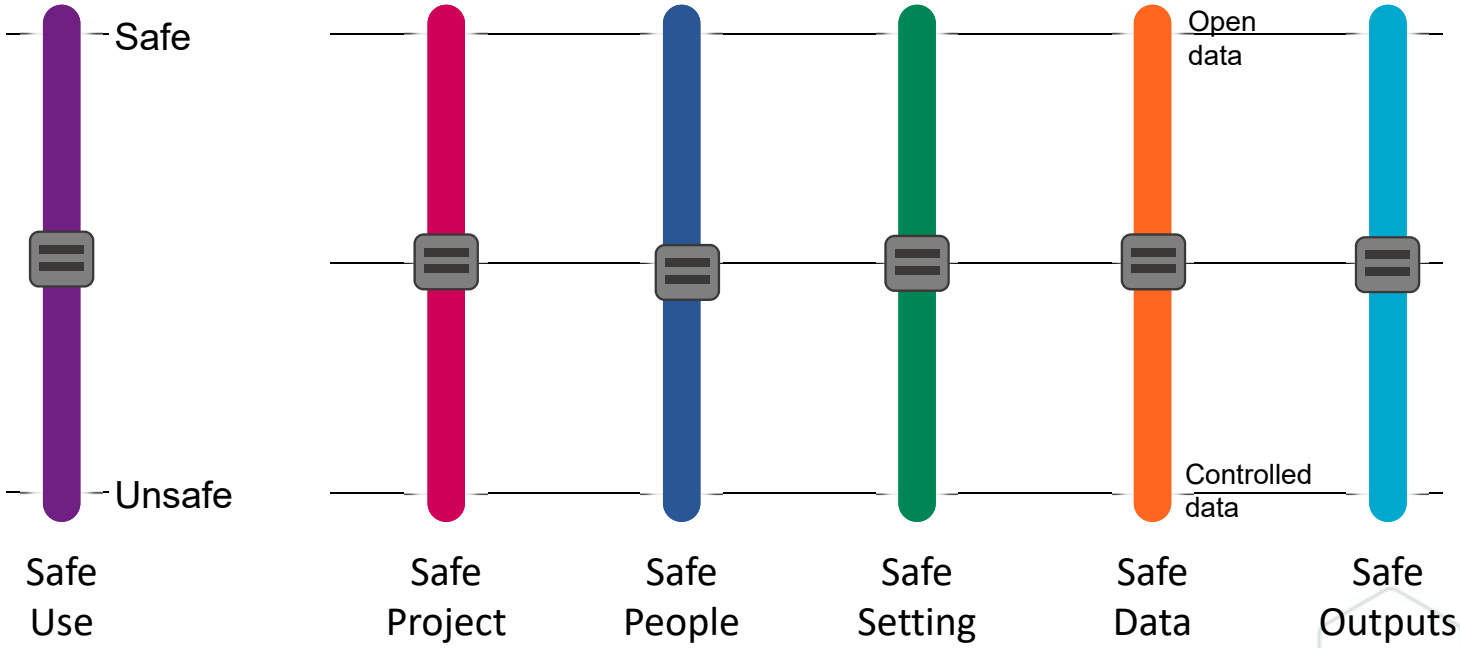


Source: SRT, 2019

The Five Safes – a framework for safe data access

The Five Safes	
Is this an appropriate use of the data?	Safe projects +
How trustworthy are the researchers?	Safe people +
Does the environment prevent misuse?	Safe setting +
Is the data detail appropriate?	Safe data +
Is there any confidentiality risk from publication?	Safe outputs =
	Safe use

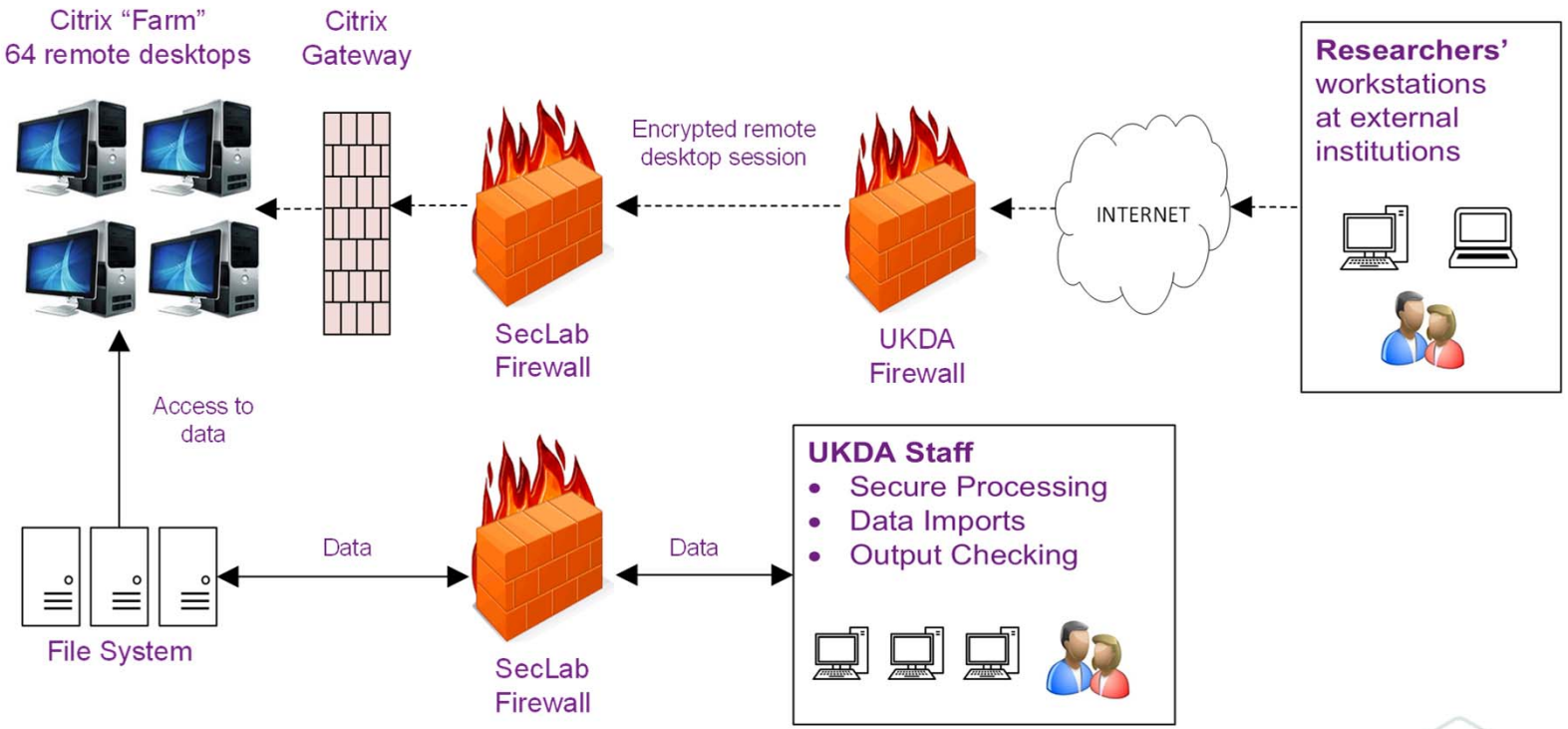
Balancing the Five Safes



UKDS SecureLab - remote access to controlled data

- Access via web-based interface that uses secure encrypted Citrix Virtual Private Network technology
- Data not downloadable, access remotely from organisational desktop or via the UKDA Safe Room or via one of the SafePods across the UK
- Outputs subject to Statistical Disclosure Control (SDC)

UKDS SecureLab infrastructure



UKDS SecureLab – 10 years remote access to controlled data for research

- 10 years operational (since 2011)
- No legal breach
- 938 active users (2021)
- Recently: Safe Room Remote Desktop Access to international controlled data
- Soon: Safe Room Remote Desktop Access to UKDS SecureLab data from abroad

Any questions?

UK Data Service

Thank you.

Beate Lichtwardt

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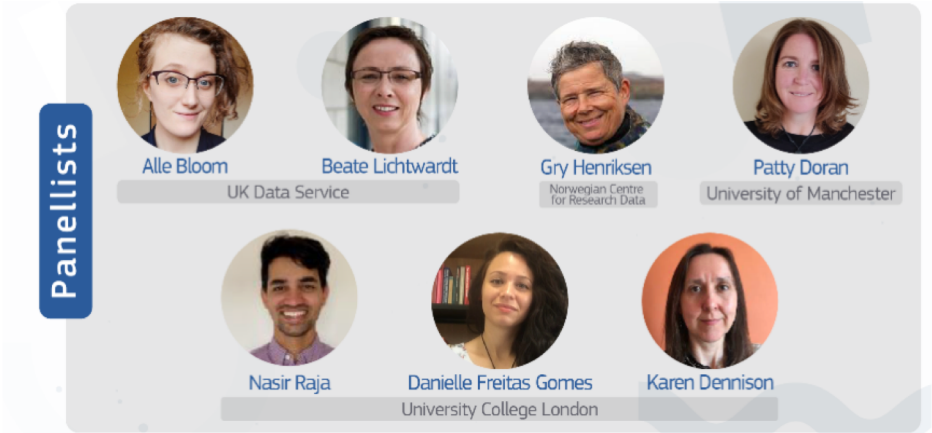
CESSDA Roadshow on Cancer & Major Chronic Diseases

1. Why is it important we continue to ask these health questions within social surveys?
2. How important is high quality data for cross-disciplinary and cross-national research?
3. How important is the support from service providers/data experts for your research workflow?
4. What is your advice for researchers trying to build on/reuse the huge amount of data already available on major chronic diseases and cancer?



cessda

Roadshow
on Circular Economy

SAVE THE DATE

28 October 2021

14:00-15:30 CEST
13:00-14:30 BST

cessda.eu @CESSDA_Data linkedin.com/company/cessda

CESSDA is an ESFRI (European Strategy Forum on Research Infrastructures) Landmark. CESSDA is an ERIC (European Research Infrastructure Consortium), a European legal entity.

Thank you for your attention!

cessda.eu @CESSDA_Data