

Webinars

for patients

Sickle Cell Disease

Topic on Focus

EuroBloodNet



Quality of life for adults living with SCD

Speaker Dr Noémi Roy

Haematology Consultant

Oxford University Hospitals NHS Foundation Trust

ERN-EuroBloodNet subnetwork: Red Blood Cell

February 2022



Co-funded by
the Health Programme
of the European Union



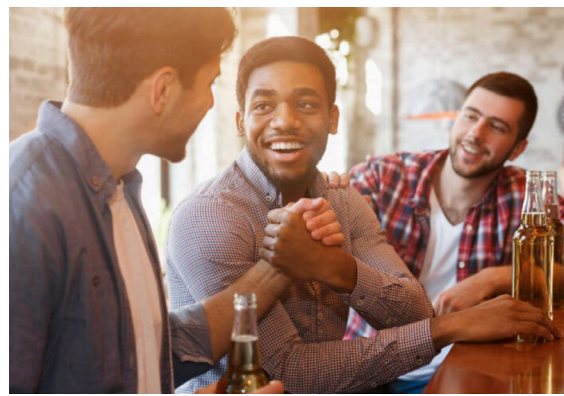
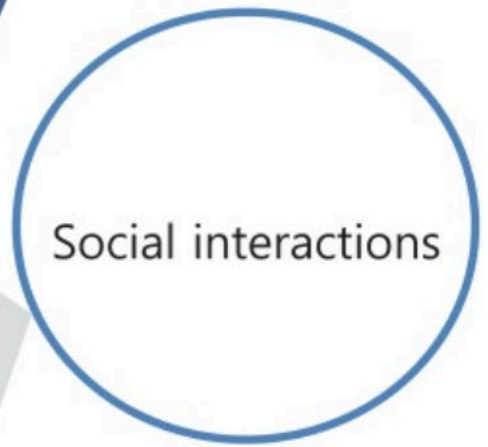
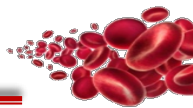
**European
Reference
Network**
for rare or low prevalence
complex diseases
Network
Hematological
Diseases (ERN EuroBloodNet)

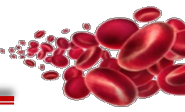
What is quality of life?



In the end, it's not the years in your life that count. It's the life in your years.

- Abraham Lincoln





How do we measure QOL?



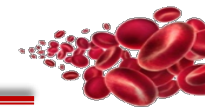
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Health Qual Life Outcomes

Health Qual Life Outcomes. 2005; 3: 50.

Published online 2005 Aug 29. doi: [10.1186/1477-7525-3-50](https://doi.org/10.1186/1477-7525-3-50)

PMCID: PMC1253526

PMID: [16129027](https://pubmed.ncbi.nlm.nih.gov/16129027/)

Health related quality of life in sickle cell patients: The PiSCES project

[Donna K McClish](#),^{1,2} [Lynne T Penberthy](#),² [Viktor E Bovbjerg](#),³ [John D Roberts](#),⁴ [Imoigele P Aisiku](#),^{2,5} [James L Levenson](#),⁶ [Susan D Roseff](#),⁷ and [Wally R Smith](#)²

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Abstract

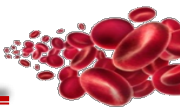
Go to:

Background

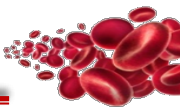
Sickle cell disease (SCD) is a chronic disease associated with high degrees of morbidity and increased mortality. Health-related quality of life (HRQOL) among adults with sickle cell disease has not been widely reported.

...

“We administered the Medical Outcomes Study 36-item Short-Form to 308 patients in the Pain in Sickle Cell Epidemiology Study (PiSCES) to assess HRQOL”



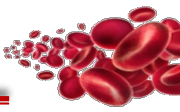
- The Pain in Sickle Cell Epidemiology Study (PiSCES)
 - longitudinal cohort study of over 300 adult patients with SCD designed to understand the relationship between pain and response to pain
 - emphasis is on variables that could be altered to change outcomes
 - enrolled 308 adult patients with SCD from July 2002 through August 2004.



Measure Eight Health Domains

A widely used PRO tool, the SF-36v2[®] Health Survey measures a range of symptoms, experiences and patient health outcomes across eight domains in thirty-six items to close measurement gaps in product lifecycles and patient care.

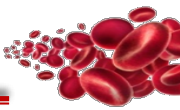
- **Physical Function**
- **Role-Physical**
- **Bodily Pain**
- **General Health**
- **Vitality**
- **Social Function**
- **Role-Emotional**
- **Mental Health**



Functional status and health-related quality of life (HRQOL) may be impaired by:

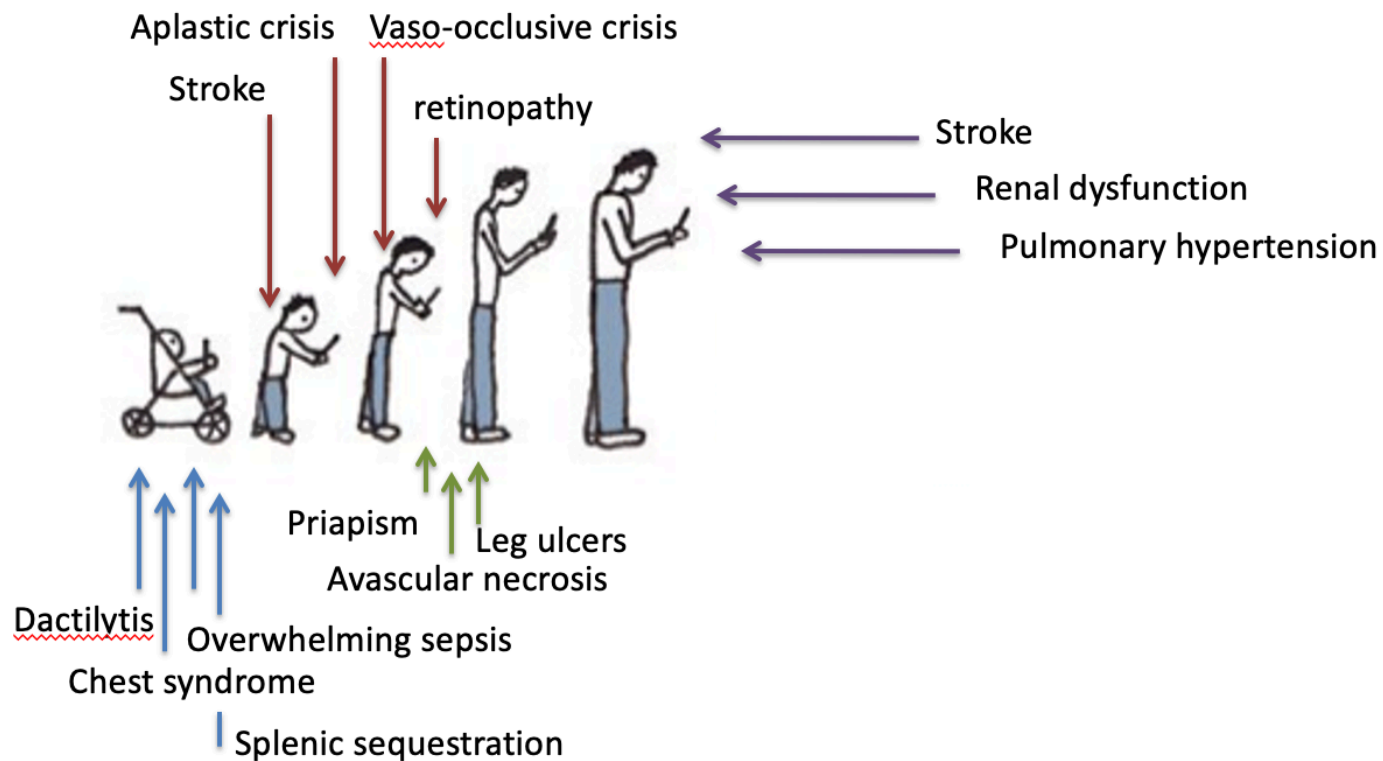
1. Pain

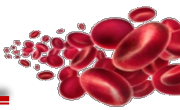




Functional status and health-related quality of life (HRQOL) may be impaired by:

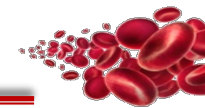
2. Disease complications



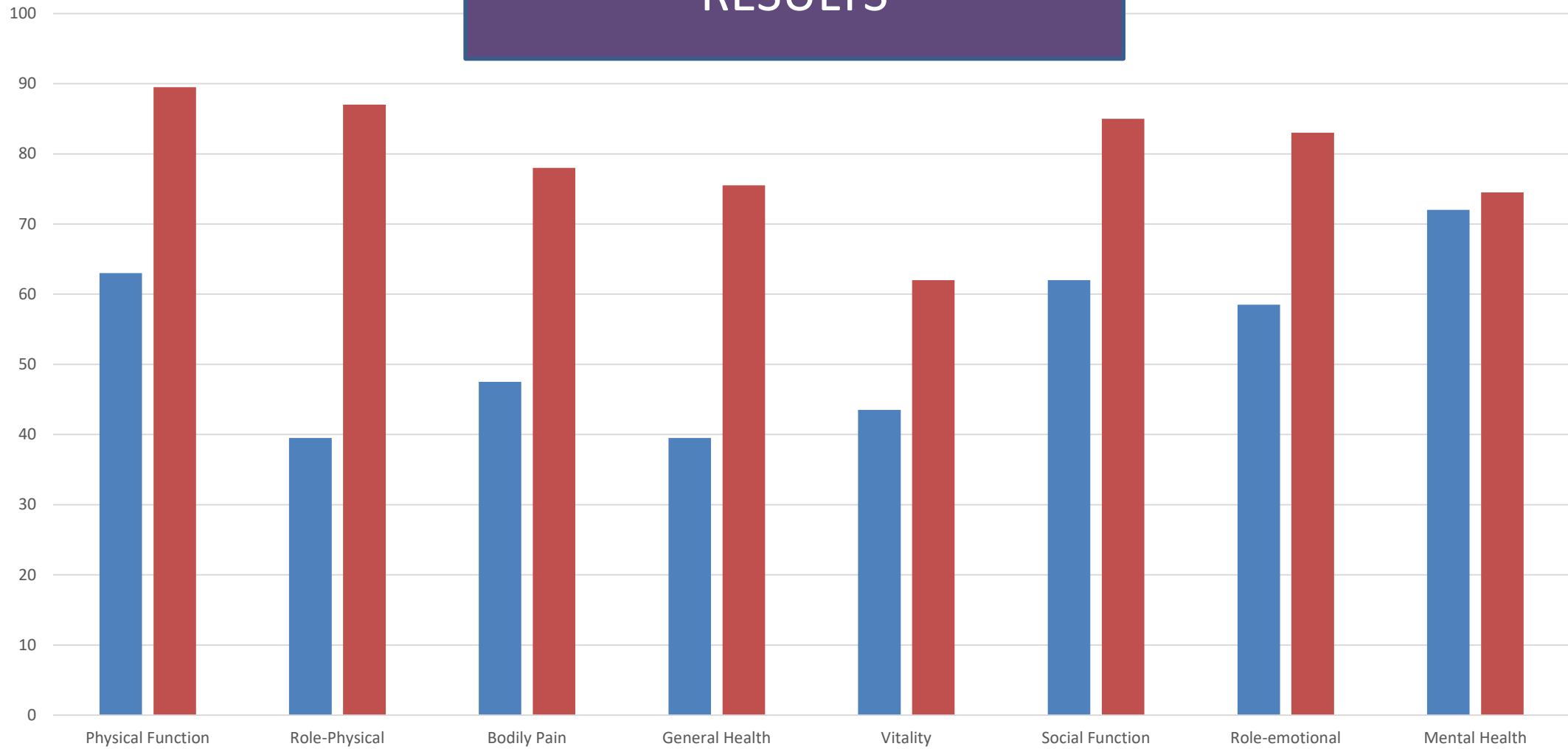


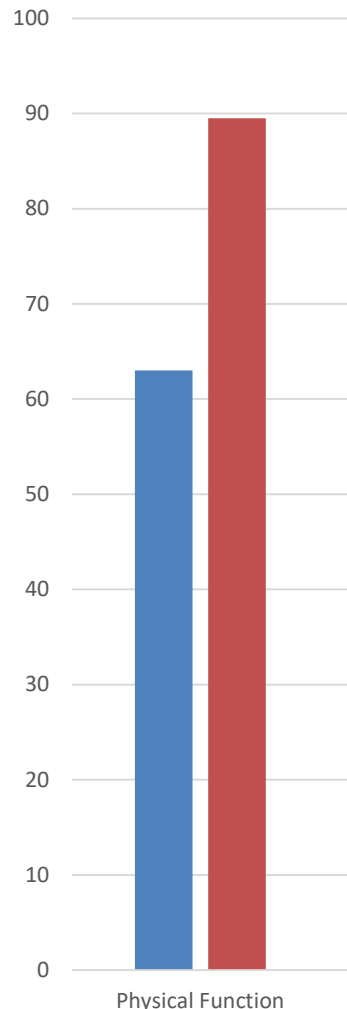
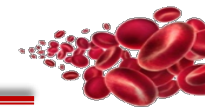
Functional status and health-related quality of life (HRQOL) may be impaired by:

1. Pain
2. Complications
3. Repeated hospitalisations
4. Fatigue
5. Having a rare disease
6. Stigma
7. Racism





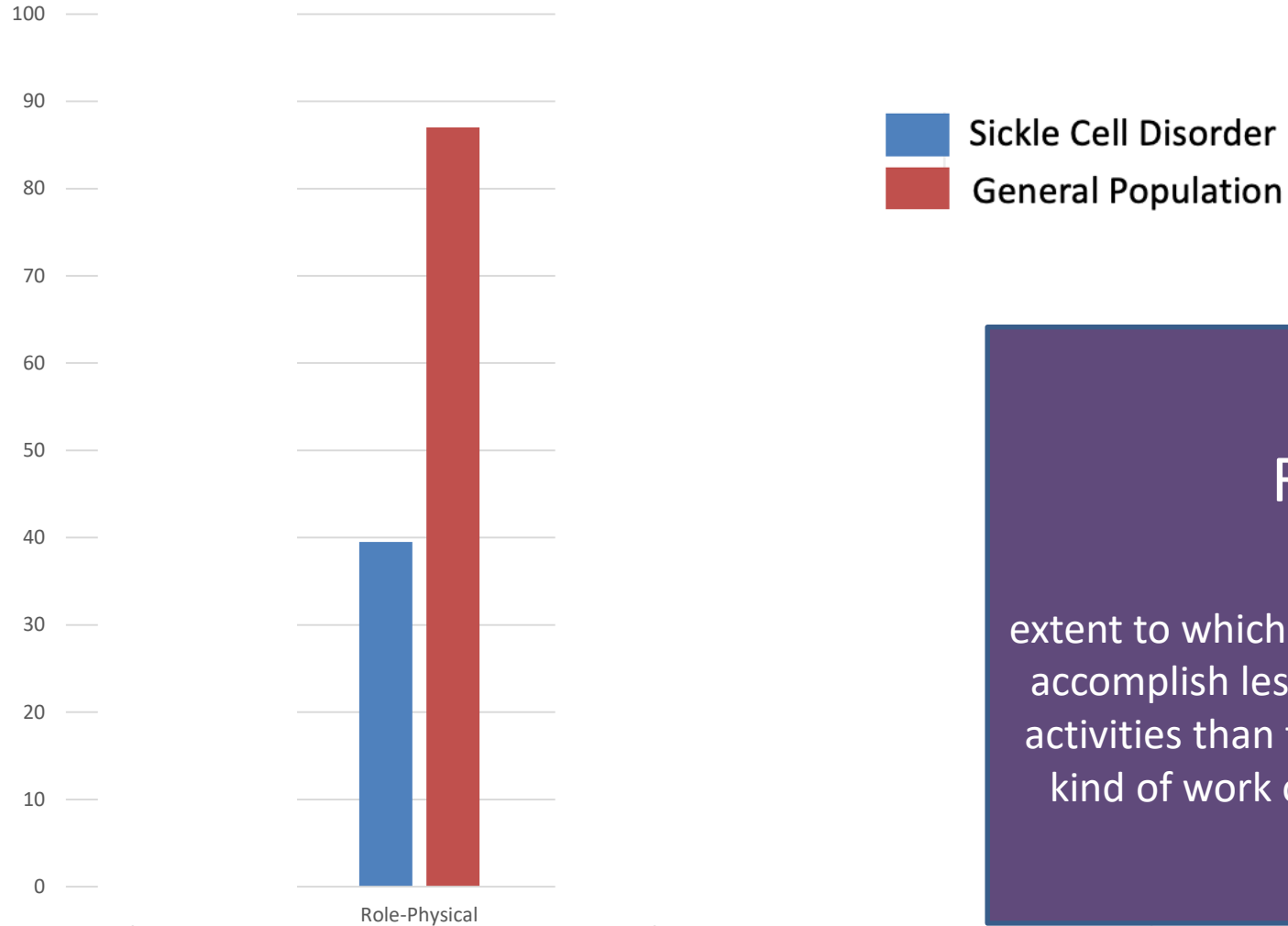
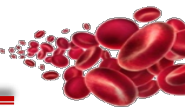
RESULTS





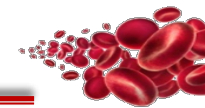
PHYSICAL FUNCTIONING

-  Sickle Cell Disorder
-  General Population

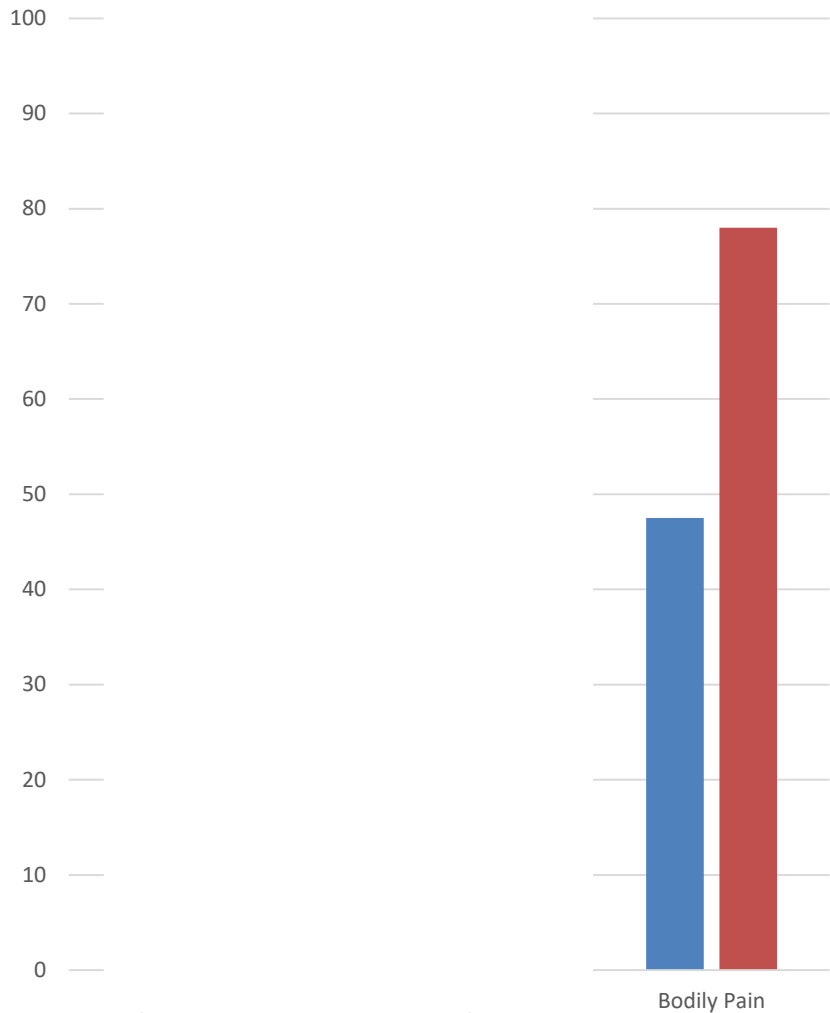




ROLE PHYSICAL

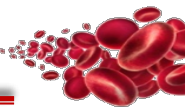
extent to which physical health causes respondent to accomplish less at their work or other regular daily activities than they would like, or limits them in the kind of work or other activities they can perform



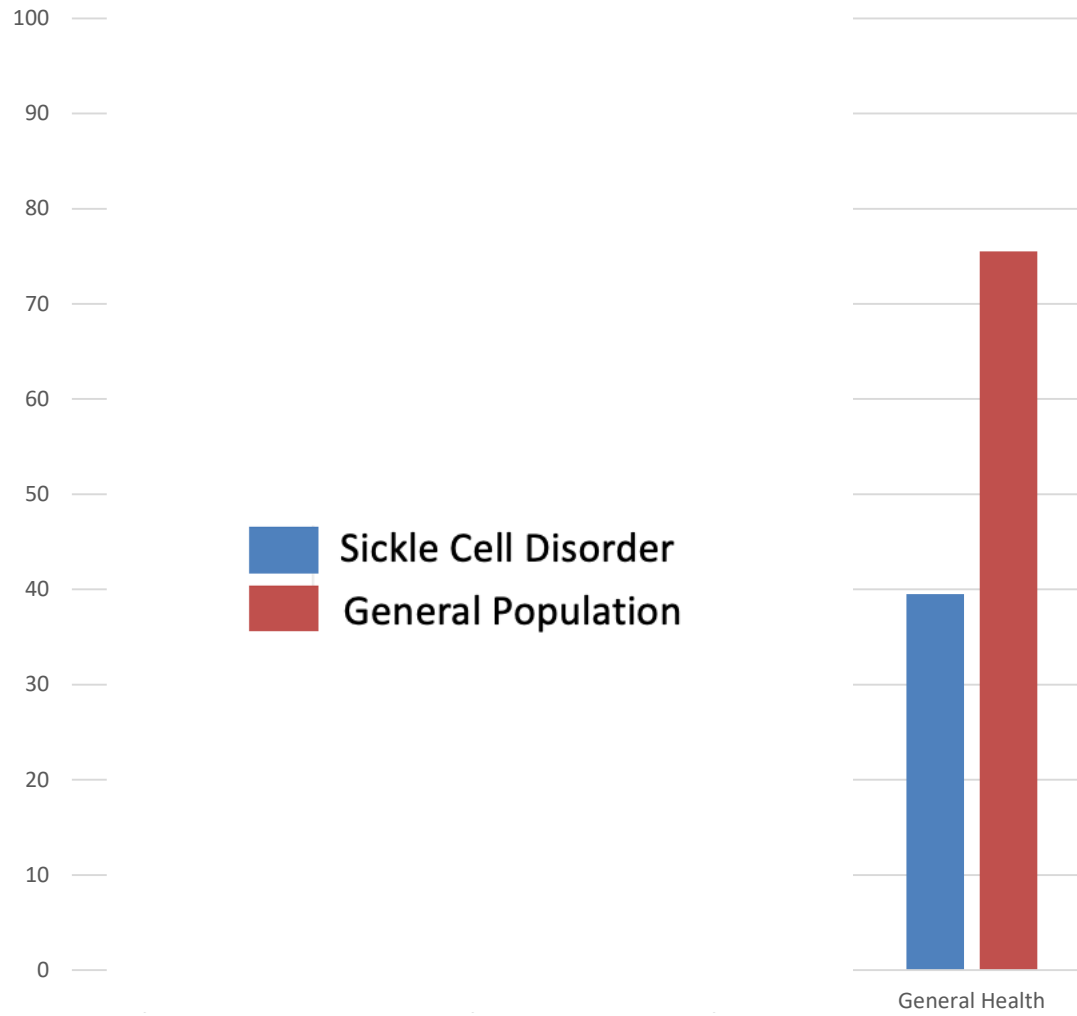
BODILY PAIN

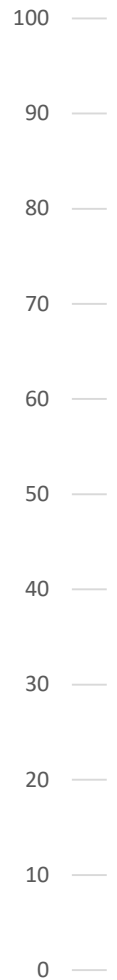
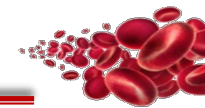


 Sickle Cell Disorder
 General Population

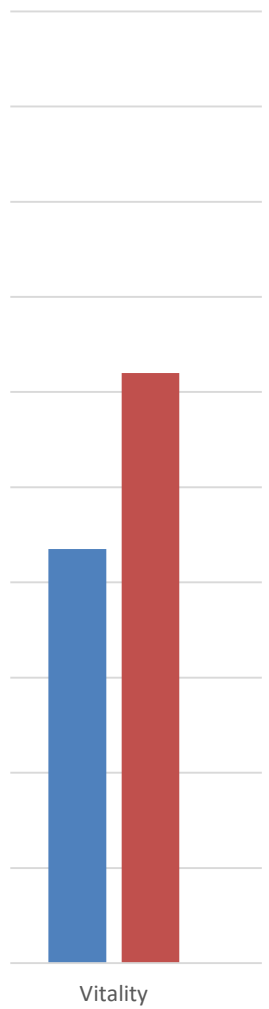
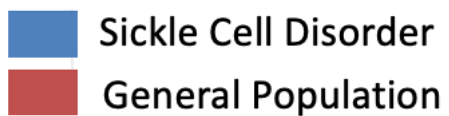


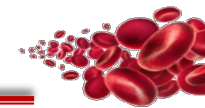
GENERAL HEALTH





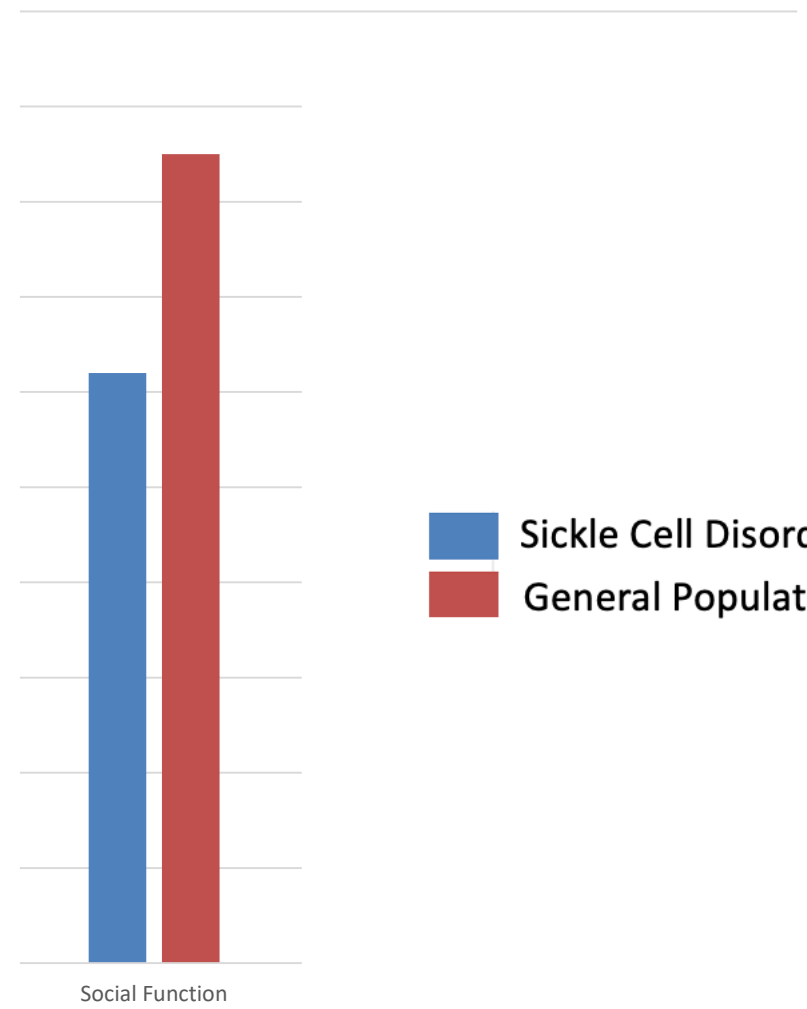
VITALITY

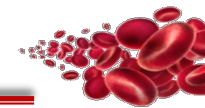




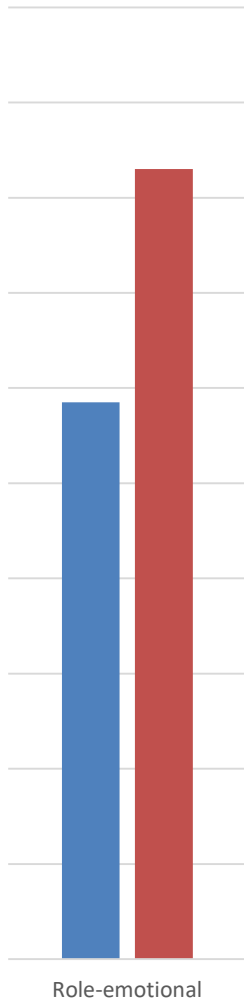
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10 —
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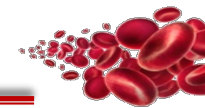
SOCIAL FUNCTIONING



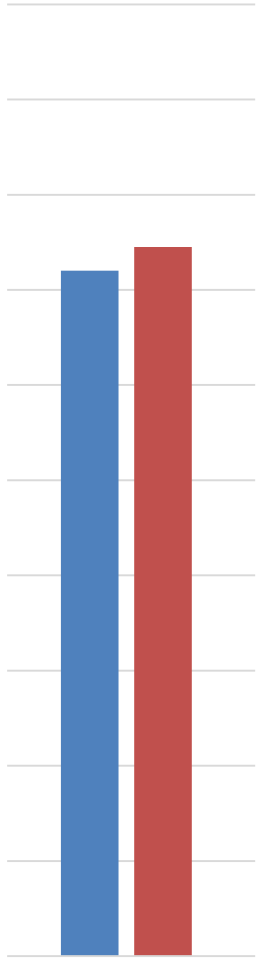


ROLE-EMOTIONAL





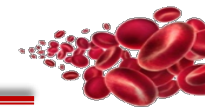
MENTAL HEALTH



Mental Health

■ Sickle Cell Disorder
■ General Population

100 —
90 —
80 —
70 —
60 —
50 —
40 —
30 —
20 —
10 —
0 —



WHAT CAN WE DO?
Ideas in Action



**European
Reference
Network**

for rare or low prevalence
complex diseases

Network
Hematological
Diseases (ERN EuroBloodNet)

Webinars

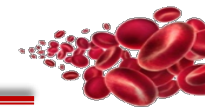
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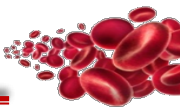
for patients

Sickle Cell Disease

Topic on Focus

EuroBloodNet





PEER SUPPORT GROUP

*a space
of
caring,
support,
and
uplift*

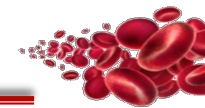
- have a chance to speak your truth
- receive support from others who understand and care
- receive inspiration from others
- have a chance to support others
- build your network of friends and supporters
- receive information to help you live a fuller life



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Hematological
Diseases (ERN EuroBloodNet)



Better research?



Peer support?

WHAT CAN WE DO?
Ideas in Action



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Sickle Cell Disease

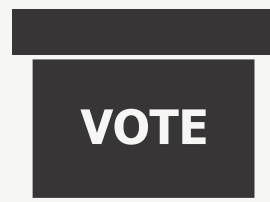
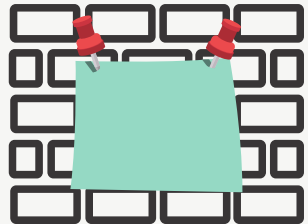
Topic on Focus

EuroBloodNet

SCD TOP TEN RESEARCH TOPICS

Lived experience and the SCD research agenda

METHODOLOGY FOR A PRIORITY SETTING WORKSHOP WITH SCD PATIENTS AND CARERS, ASCAT 2019



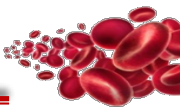
And finally: Celebrate! And group debrief.



SCD TOP TEN RESEARCH TOPICS

Lived experience and the SCD research agenda

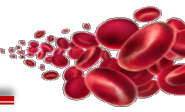
OUTCOMES OF A PRIORITY SETTING WORKSHOP WITH SCD PATIENTS AND CARERS, ASCAT 2019



- 1 How can we find a universally available cure for sickle cell disease?
- 2 How can we improve quality of life for people living with sickle cell disease?
- 3 What are the implications of sickle cell disease for work and education? How do we advise people, employers and schools?
- 4 How do we manage acute pain to prevent hospitalisation?



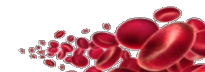
- 5 How does staff diversity or lack of diversity affect the way patients experience racism, discrimination and stigma?
- 6 How do we harness the political agendas to improve care for sickle cell disease?
- 7 How can we optimise pregnancy for mother and baby in sickle cell disease?
- 8 What complementary therapies work in sickle cell disease, including CBD oil and cannabis?
- 9 How do we manage chronic pain?
- 10 What is the impact of a comprehensive care team on outcomes for people living with sickle cell disease?



2

How can we improve quality of life for people living with sickle cell disease?





My Profile

Personal Details:

Edit



Name: **D j**
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07834626103

General Practitioner:

Edit

Dr Hope
Owen Road Surgery
Lancaster

Consultants:

Edit

You have not added any consultants.

Dr Xlh Expert
Speciality:
Royal Berkshire Hospital
Reading

Speciality:
Glasgow Royal Hospital
Glasgow

Other Studies:

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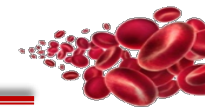
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StudyName: **nihr bioresource**
REC ID:
Lead Research Centre:
Contact Name:
StudyName: **test 123**
REC ID:
Lead Research Centre:
Contact Name:

Diagnosis:

Edit

Osteogenesis imperfecta
Sickle cell anemia
Multiple myeloma

My Contribution to Research

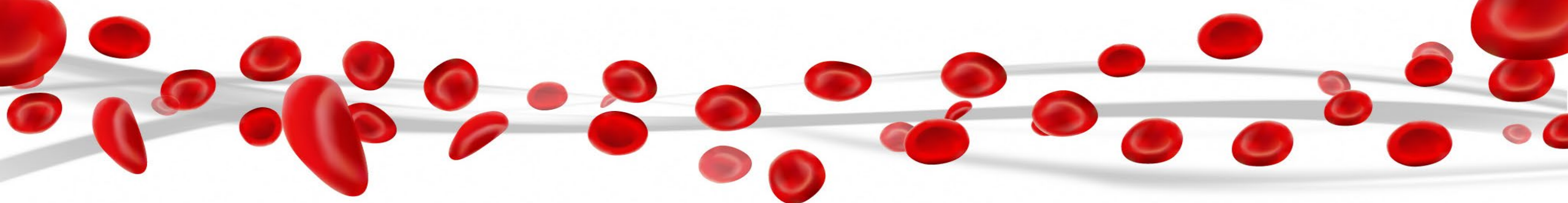


Better research?



Peer support?

Let's discuss!



Discussion

