



*Information, Counselling
and Caring for those with
Sickle Cell Disorders
and their families*

*Charity Reg: 104 6631
Company Reg: 284 0865
www.sicklecellsociety.org*

1st National Conference Treating Haemoglobinopathies 2020

John James OBE Sickle Cell Society

*London
16 January 2020*




Celebrating

40
YEARS

1979 - 2019

What we do


- ▶ We advocate for people living with SCD and their families
 - ▶ We mobilise and empower people with SCD and their families
 - ▶ We raise awareness and educate external stakeholders
 - ▶ We influence national policy for SCD eg. NHS England, Department of Health and Social Care and The National Institute for Health and Care Excellence (NICE)
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GSK/King's Fund Impact Award Winners 2018



Why do we do this?

- ▶ SCD has a devastating impact on the lives of individuals and families eg. strokes, renal dysfunction, necrosis of the hip.....
- ▶ Severe morbidity and mortality
- ▶ 20-30 year reduction in life expectancy
- ▶ Poor experience of care
- ▶ Treatments are limited and have been for decades.... although this is changing

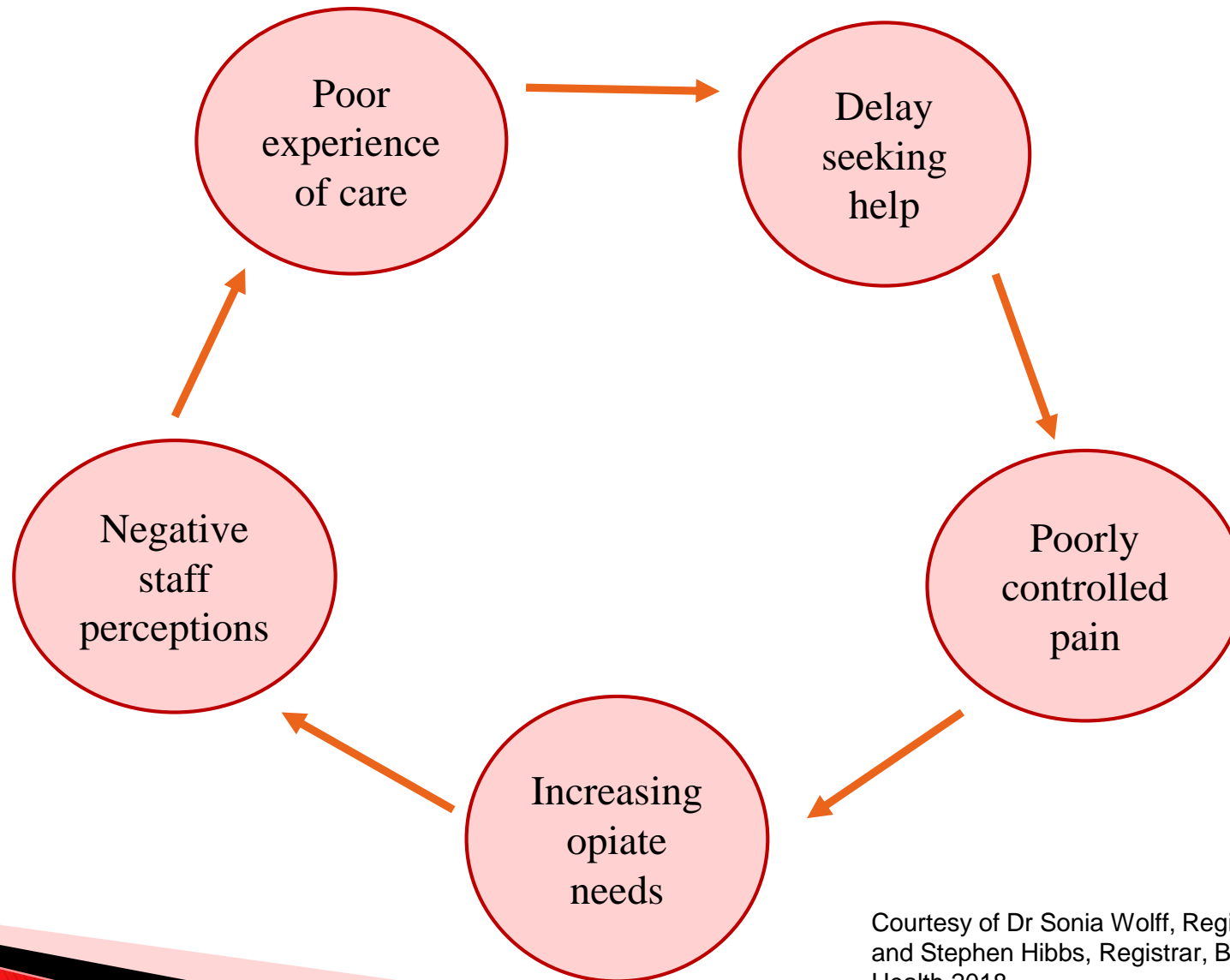


SCD is an underserved condition

What do people with SCD/Families tell us?

- ▶ SCD inequalities eg:
 - NHS England policy on transplantation
 - Individual Funding Requests (IFRs)
 - Access to Apheresis
 - Access to psychological support
- ▶ Stigma
- ▶ Sub-optimal care – Accident and Emergency
- ▶ Delay in seeking help
- ▶ Prejudice
- ▶ Limited treatments
- ▶ Hydroxyurea/Hydrocarbamide myths
- ▶ Limited means (60% of all patients live in the lower quartile of deprived areas)

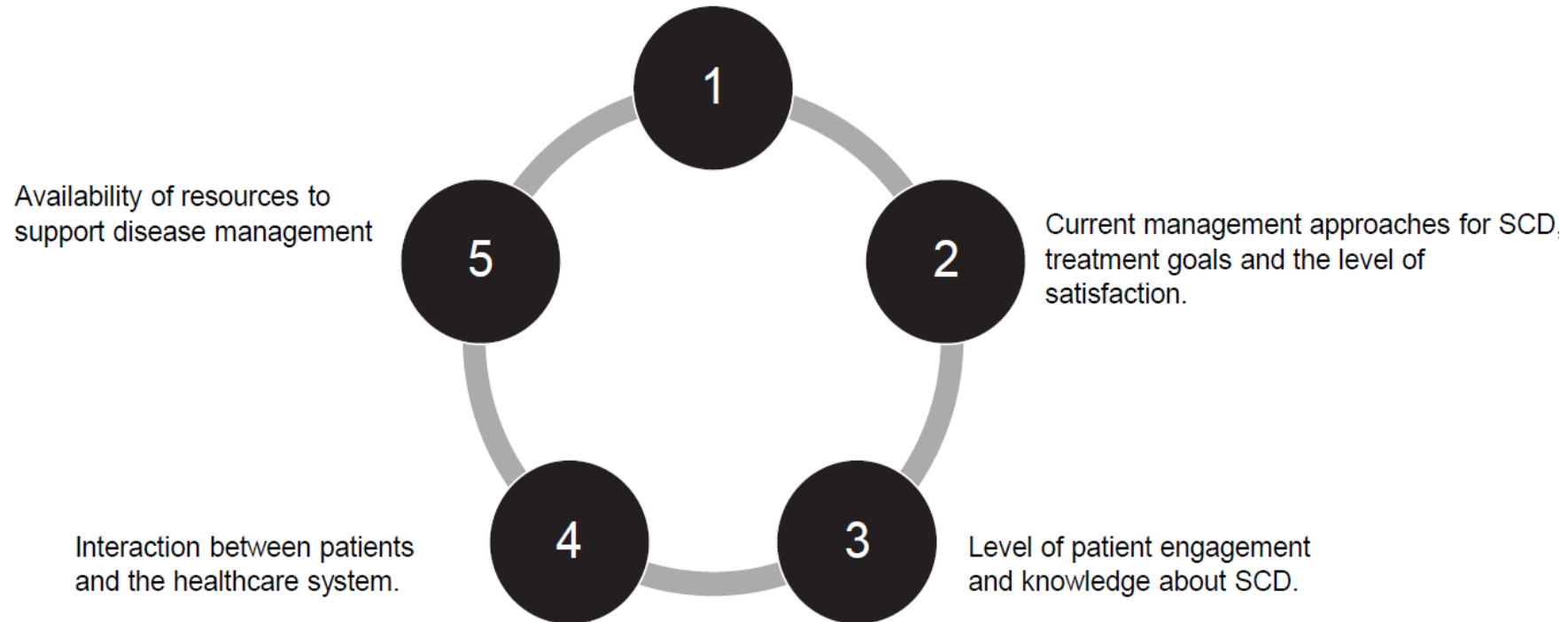
Cycle of Harm



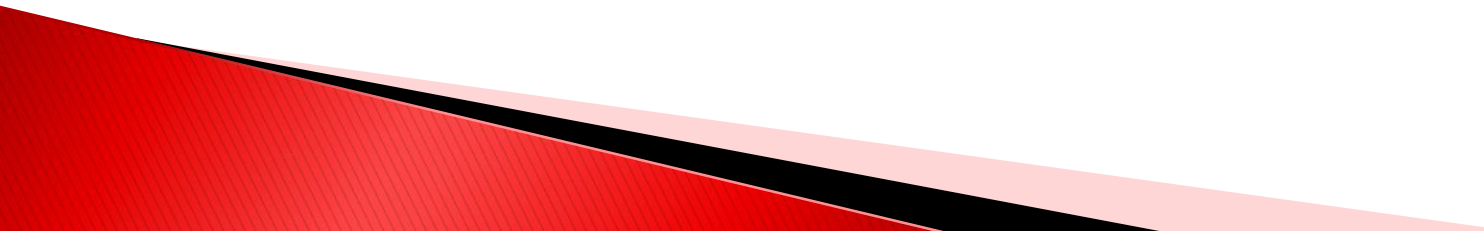
Courtesy of Dr Sonia Wolff, Registrar,
and Stephen Hibbs, Registrar, Barts
Health 2018

Sickle Cell World assessment Survey (SWAY)


The impact of SCD on patients in terms of symptom, emotional and economic burden and the impact on daily living (e.g. burden of VOCs and pain etc).



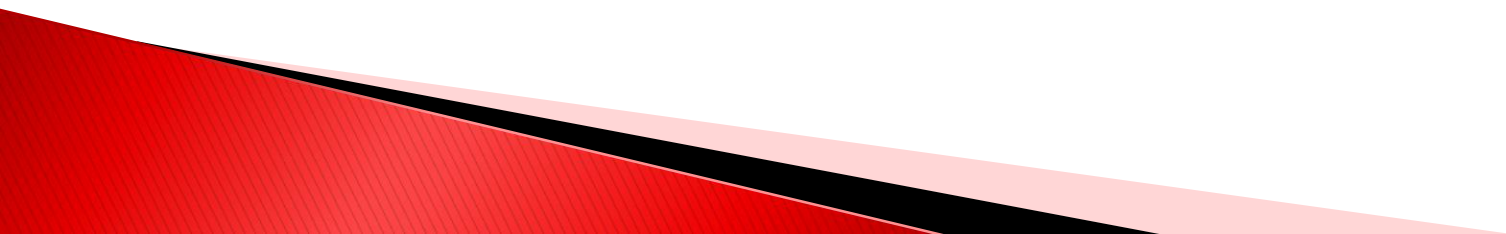
Highlights from SWAY

- ▶ After VOCs, fatigue is the most frequently reported SCD symptom by patients and has a high impact on their QoL
 - ▶ Patients require emotional and logistical support managing their SCD and rely mostly on their parents and relatives
 - ▶ SCD patients often miss work or have reduced work hours, which can lead to losing their job
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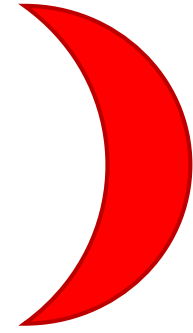
What are the three main goals of people living with SCD

- ▶ Improving their quality of life
 - ▶ Preventing worsening of their SCD
 - ▶ Reducing number of severe pain crises
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THE FUTURE ?



Sickle Cell Society



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