

# Innovating to improve the lives of adolescents living with a long term conditions



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# Aims



Outcomes  
Experience  
Better value care

# Why work differently?

*“What is needed is a **common vision** that is strong enough to bind all the agencies together while taking account of different perspectives ... The future must be one of a **holistic approach** to the child or young person.”*

**Ian Kennedy**

# Better value care

## **NUMBER CRUNCHING**

**£14 mn spent across London on SCD  
2010/11**

**No of children admitted with SCD  
doubles in adolescence**

**24% percentage of children with a long  
term condition in H&F**

# Co-production

- Reciprocity: everyone has something to give
- Adding value through organisation not structure

# The community

Rachel Abraham Lucy Abrahams, Ed Abrahamson Lydia Alexander  
Huda Al-Hadithy G hida AlJuburi D ominique Allwood P antelis  
Angelidis Antony Aston Carsten Bantel , Carole Bell Derek Bell  
Fernando Bello T ofunmi Benson A bi Berger Samira Bin Omar,  
Mitch Blair Martin Block Naomi Breese Michael Brown A lison  
Cameron Fisa Canter Josip Carr Cat Chatfield Hilary Cass Subarna  
Chakravorty, Tagore Charles , Mydhilli Chelappah Michael Chiu  
Gavin Cho D avid CoxPaul Craddock Daniella Collis Peter  
Crutchfield Phil Daly Selwyn Dexter S herry Diaz Thomson Samam  
Dirir, Bartek Dziadosz C atherine ElwigYechiel Engelhard O nyeka  
Ezenagu, F atou Faye Gaby,Haddy Faye M artin Fischer  
Flonah,Jonathon Fluxman, Nigel Giam A ndrew Goodstone Stuart  
Green Rachel Griffin Dianne Hag Sara Hamilton Scott Hamilton  
Dougal Hargreaves Lynette Haynes Christopher Huckvale Jane  
Kelly Sujatha Kesavan Anna Campbell Robert Klaber Roger  
Kneebone M ark Larsen Mark Layton , J ohn Lee Clai re Lemer  
Renton L'Heureux Andrew Long Lauren Lyon Chloe Macaulay Lucy  
MacCallum Ian Machonochie S ylvere Magona Aghileh Djafari  
Marbini M ichael Marmot Jason Maroothynaden Laura Marshall  
David McCoy, D onald McLeish C hris McRobbie C hristine Mead  
Charlotte Mensah Isobelle Mensah Mrs Mensah Daniel Miyares Kos  
Mohamed John Moore John Moreiras Fiona Moss Gordon Mundie  
Katrina Nash Faith Ndirangu C omfort Ndiva Asaah Nkohkwo Jackie  
Nkohkwo Zita Noone Patrick Ojeer Ogo Okoye Carlotta Olason Mary  
O'Mahony Marion Ong Lola Oni Elizabeth Paice Tim Patch Gayan  
Perera Clare Perry Neil Pfeiffer Karen Phekoo Leila Powell Neville  
Pursell S abeena Qureshi Tetteh, Sinan Rabee, Asif Rahman  
Rebecca Salter Rebecca Rawesh Dan Redsull J anette Reddick  
David Rose Clare RossTammy Rothenburg Jane Runnacles  
Nemonique Sam Krishni Singanayagam J ohn Spicer catriona  
stalder TeeEllie Tickner Nafsika Thallassis Marie Trueman, Roshni  
Vadher Robbert Van-Heel S tephen Ward John Warner Samir  
Wassouf Mando Watson David Welbourn Will Warburton Ingird  
Woolf 55 mothers at Queen Charlotte's antental clinic, 15 parents  
at NWL childrens centres, 12 parents at an Arab/Bangladeshi after  
school club, 25 parents from Imperial maternity service user group

Primary care secondary care social services public health third sectorService users

commissioners education/academia managers graphic/software design and film

# McDonalds Kentish Town



# Hackathon @ St Marys



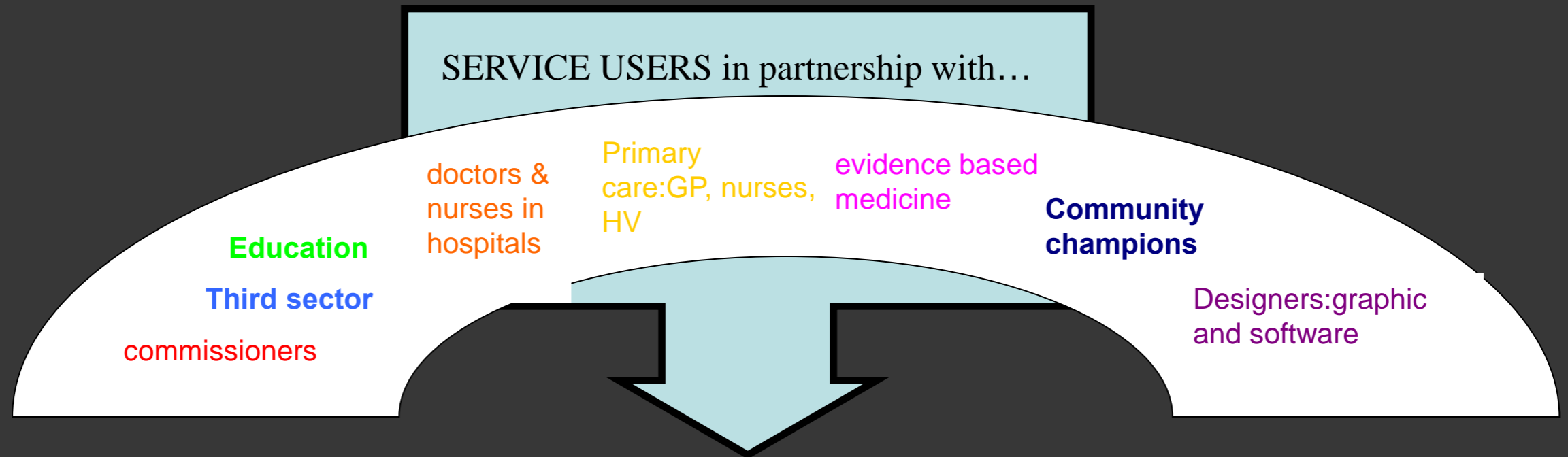


*“I am in pain worse than childbirth and four people ask me my past medical history before I am given morphine”*

SDT, 28 year old patient

*“when we see a young person in crisis at 3am we cannot access information about previous admissions to intensive care, the dose of morphine they usually get given or even their usual medications, the only solution is that all children with a long term conditions carry their own health records”*

Emergency Department Consultant



### ‡Community based networking event:

in partnership with local hospital: at age 9-12 marking the start of a 'transition'

### ‡Social network:

Enabling young people to form a face to face network with 'people like them' for support,

### ‡Personalised care plan app

for mobile phones enabling young person to self manage

‡Co-designed information app for mobile phone developed by young people for young people

### Raising awareness

In communities & in medical workforce

## **MEASURE AND EVALUATE:**

### **Short term intended outcomes:**

- 1.Improved well being**
- 2.Increased educational attainment**
- 3.Reduced non elective admissions**
- 4.Reduction in hospital admissions**
- 5.Shorter in hospital stays**
- 6.Reduced morbidity and mortality**

### **Longer term outcomes:**

- 1. Increased self esteem and mental health**
- 2. Reduction in long term complications**
- 3. Better self management**
- 4. Improved relationships with health services**
- 5. Improved life outcomes:**

# **ECONOMIC EVALUATION**

# Impact

*“... the way in which you have addressed the issues has been fantastic, involving many agencies, and most importantly involving the children and their families. It has been creative and sensitive and dynamic and thoughtful.”*

Carole Bell, Commissioner for Children's Services INWL PCT

# Impact

Functional Relationships

Commissioning

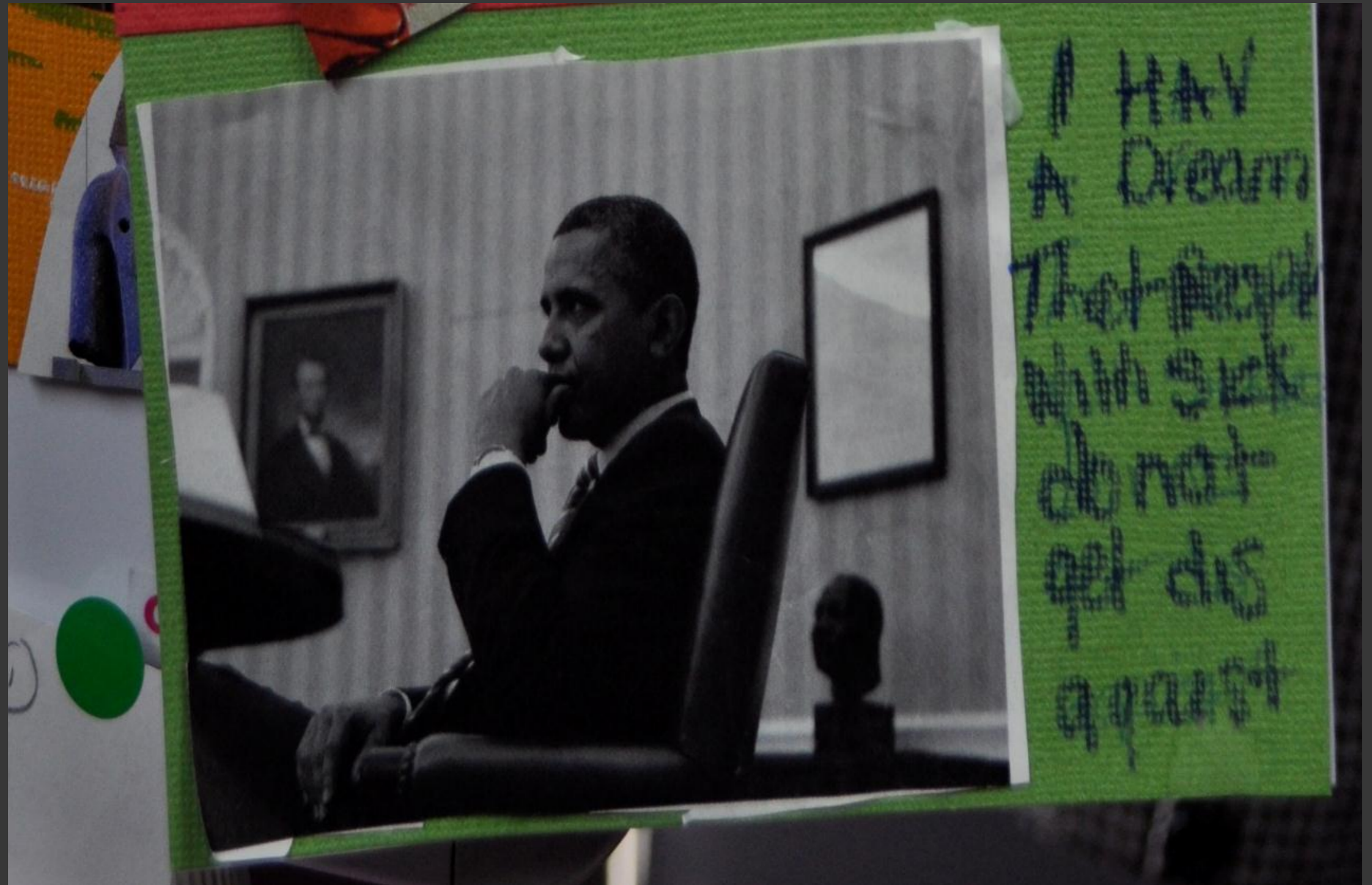
Research

Innovation

Workforce

Patients

Systemic spread



***“I have a dream that people with sickle do not get discriminated against”***

Questions?