



Nicola Baldwin Supporting Your PPI



Nicola Baldwin

Playwright and Scriptwriter

UCL Creative Fellow 2019-2020

Royal Literary Fund 'Showcase' (Digital) Fellow

Patient and Public Involvement

- NIHR funding obligation
- Valuable research tool
- Dissemination route direct to public
- AMR necessitates shift in public opinion
- Precision AMR is a great science story

Public Engagement - Entertainment

- To provide (someone) with enjoyment
- To provide hospitality / welcome to visitor or guest
- To give attention or consideration to idea or feeling

PPI Phase 1 June-October 2020

- Workshop 1: JUNE 2020 Discuss and decide Precision AMR themes
- Teams bid for topics

- Workshop 2: JULY 2020 Allocate teams/ topics to develop
- 'Dating' service to connect artists/ partners
- Workshop for supporting artists / partners
- Teams submit project proposals for seed funding

- Workshop 3: OCTOBER 2020 Present work in progress
- Discuss PPI delivery in Phase 2

PPI Benefits for your team

- Design and deliver effective engagement tailored to you
- Meet colleagues informally to discuss your work
- Reflect on aims and progress
- Discover new perspectives and capabilities
- Document your project
- Create legacy
- Enjoy results



Sue Lee What Matters To Patients Now?



Sue Lee

Director, Hexagon Supply Chain

PPI Advisor

Patients today

- Tech savvy
- Informed
- Entitled
- Participate in their care
- Talk to other people
- Take personal responsibility
- Demand decision making power

Tech solutions

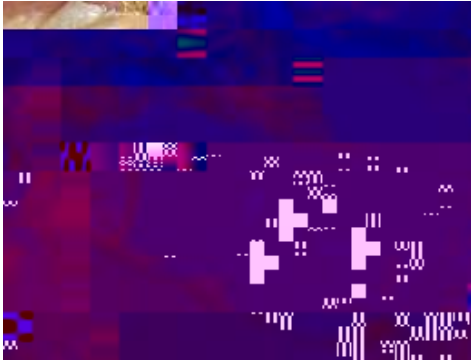
- Genetic testing
- Personalised medicines
- Cell and Gene Therapy
- In 2017 survey
 - 79 percent of patients want to receive text messages from their healthcare providers, and
 - 73 percent would like to be able to send text messages to their providers.
- Home healthcare & Direct to Patient
- Telemedicine
- Fitbits / step counters / heart monitors

Case Study - The AKU story

- Alkaptonuria - Black Bone Disease was the first genetic disease ever identified over 100 years ago
- Affects one in every 250,000
- Causes a build-up of acid in the body which attacks bones and other tissue, turning it black and brittle.
- This causes severe joint damage in patients, and can result in heart disease

(With thanks to Dr Nick Sireau of AKU Society)

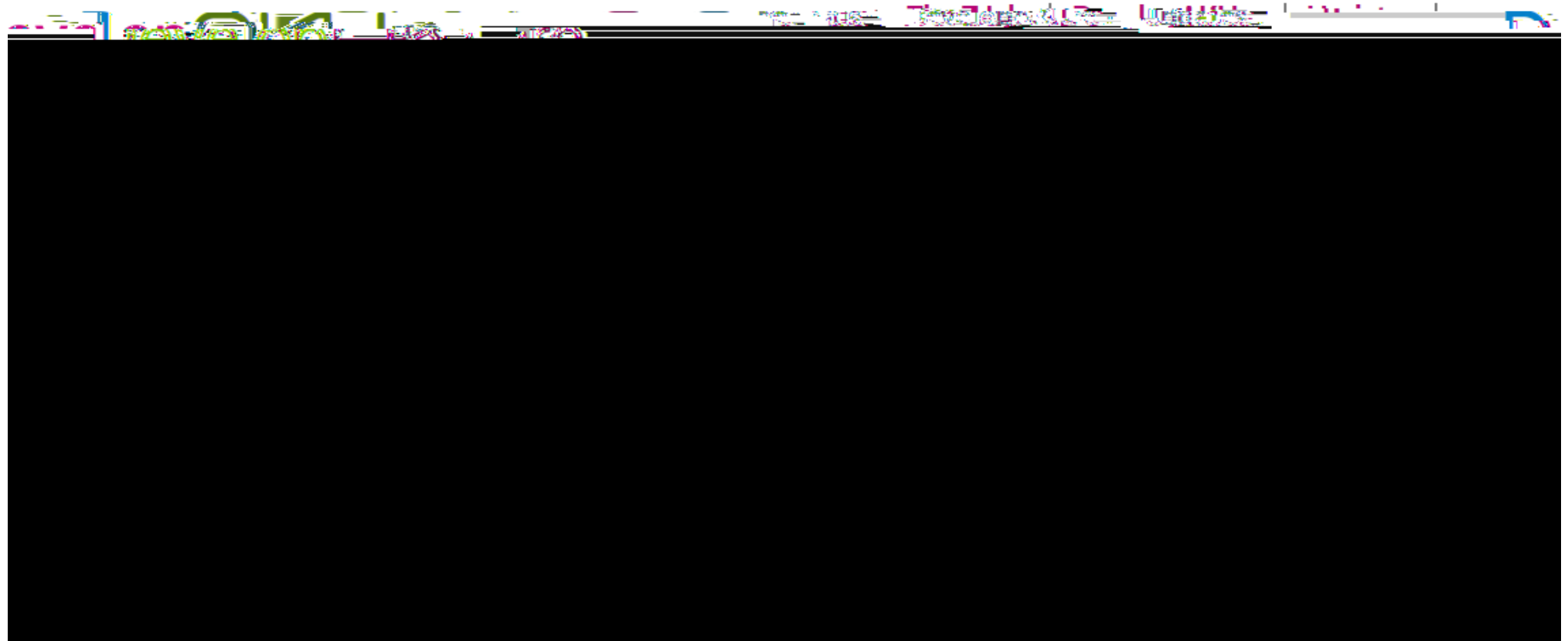
Symptoms and Patient group



Trial

- Trial SONIA 1: Suitability of Nitisinone in Alkaptonuria 1
 - 3-month phase II study
 - UK/Slovakia
- SONIA 2: Suitability of Nitisinone in Alkaptonuria 2
 - 4-year phase III
 - UK/Slovakia/France
- SOFIA: Subclinical Ochronosis Features
 - in Alkaptonuria
 - Cross-sectional study
 - UK

Crowdfunding a cure



Not just money

- Found new patients
- Raised awareness
- Created country specific patient groups, social media networks
- Training days
- Funded parent travel for study

Engagement