



Department
of Health &
Social Care

Nicola Baldwin – Supporting Your PPI



Precision AMR

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

Precision AMR PPI

- PPI budget allocation 0.50% total Precision AMR grant
- Consolidate PPI strategy to maximise impact
- Plan PPI as process not just event
- Design PPI that works for your team

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 Phase 2 – November 2020-June 2021

- **Event / Activity: MARCH 2021**
- (NOVEMBER- FEBRUARY 2021) Supported development of PPI activity
- PPI event / activity at your site or partner organisation

- **Festival: MAY 2021**
- **‘Rise Of The Resistance’** 2-day Festival, Bloomsbury Theatre / UCL
- Precision AMR Themes: Drama, musical, monologue, performance
- Talks, panels, demonstrations, workshops, exhibition

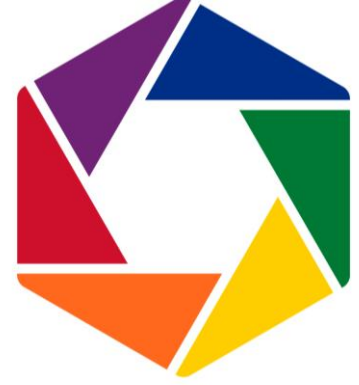
PPI Benefits for your team

- 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



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Sue Lee – What Matters To Patients Now?



Precision AMR

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

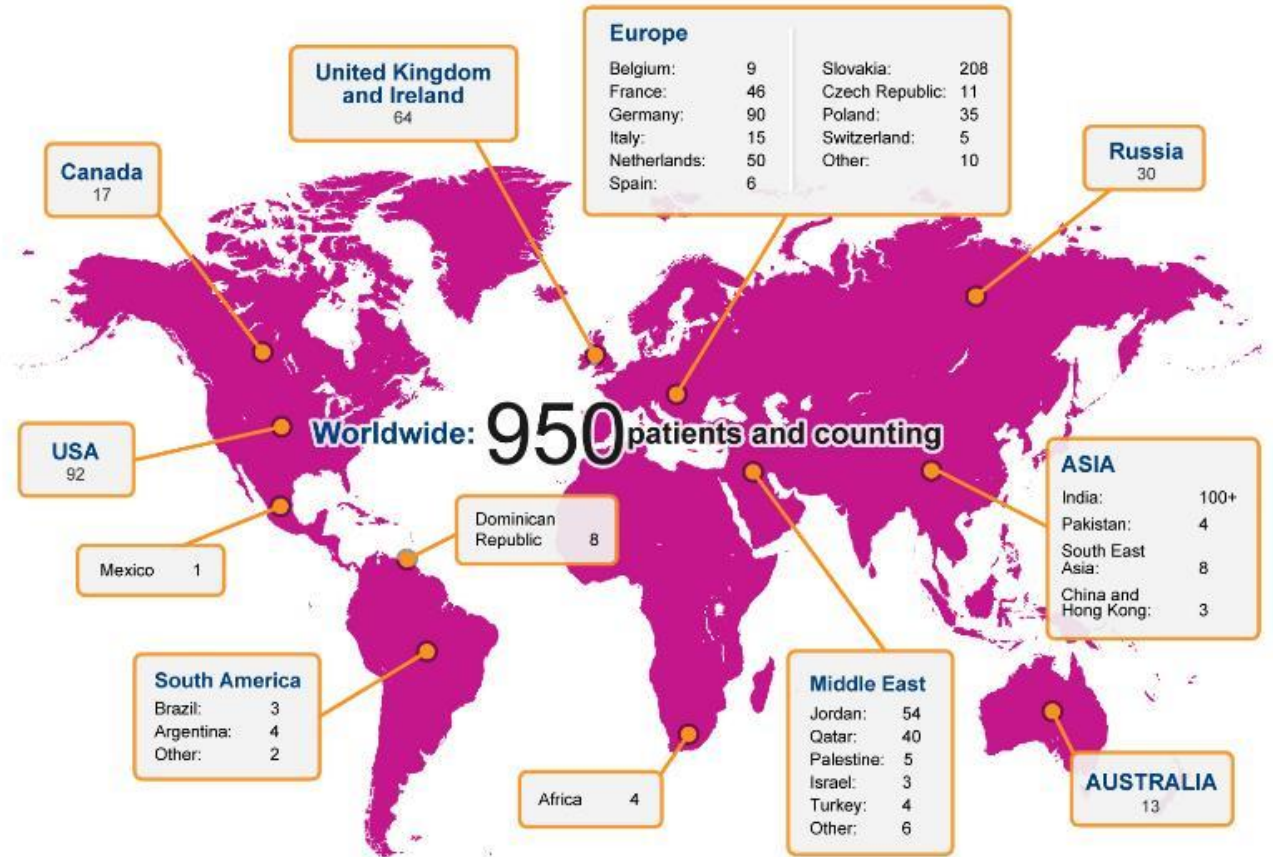
- **Genetic testing**
- **Personalised medicines**
- **Cell and Gene Therapy**
- In 2017 survey
 - 79 percent of patients want to receive text messages from their healthcare providers, and
 - 73 percent would like to be able to send text messages to their providers.
- Home healthcare & Direct to Patient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

DevelopAKUre

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History of DevelopAKUre

The DevelopAKUre programme is a series of major international clinical trials, run by a consortium of 12 European partners. It aims to study a potential new drug, called nitisinone, and assess its potential effectiveness in treating the rare disease, alkaptonuria (AKU).

What are AKU and nitisinone?

 AKU was the first genetic disease ever identified and was discovered by Sir Archibald Garrod in 1901. Patients experience a severe osteoarthritis which turns bones black and destroys their joints. More than 100 years later, AKU still has no cure, nor treatment.

Not just money

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

Engagement – reaching patients and public

- **Workshop**
- **Theatre**
- **Popular culture**
- Brings informed patients
- Changes public opinion
- Changes public behaviour
- Reduces demand for unnecessary and inappropriate prescriptions
- Encourages participation