

## Lucy Watts MBE, MUniv, FRSA

D.O.B. 02.10.1993  
Address: 16 Swans Green Close, Benfleet, Essex SS7 3PE  
Mobile: 07591 592097  
Email: [lucy@lucy-watts.co.uk](mailto:lucy@lucy-watts.co.uk)  
Website: [www.lucy-watts.co.uk](http://www.lucy-watts.co.uk)  
Twitter: [www.twitter.com/lucyalexandria](http://www.twitter.com/lucyalexandria)  
LinkedIn: [www.linkedin.com/in/lucyalexandria](http://www.linkedin.com/in/lucyalexandria)

### Personal Profile:

A highly competent, hardworking, motivated, conscientious, trustworthy, and dependable individual with an outstanding work ethic, who can apply knowledge and skills to ensure an extremely high standard of work and full commitment to duty. Detail oriented but with an ability for big picture thinking, and practical and solution-focused with a talent for problem solving, A skilled and effective communicator, proficient at communicating complex topics and information to individuals in a language they can understand to be informed and empowered, as well as being open and approachable, reflective and contemplative, and learning, growing, developing, gaining insight and gleaned new knowledge with every encounter and interaction. A thirst for knowledge and adept at assimilating, assembling, and then applying that knowledge and information in future work, including to strengthen arguments, to give background and context as well as to relate information, issues, or arguments to public affairs, to legal and ethical issues and to collective and personal lived experience. A skilled networker, negotiator, and a persuasive leader, able to influence others and build confidence and trust easily. By nature, an articulate, engaging, and compelling public speaker, and a powerful and inspiring public representative and advocate. Able to operate at a highly public and specialist level in one moment, in the next working directly with beneficiaries and the public, and on a grassroots level, with seamless adjustment in technique and approach to meet all individuals on their level. Devoted to upholding The Seven Principles of Public Life and being an effective advocate for the organisations being worked with and for, faithful to ensuring positive representation, and remaining connected to the communities for which the work concerns and involves. Confident and able to be assertive and authoritative when needed, whilst also utilising more collaborative, democratic, participative, coaching, and affiliative styles whenever possible and appropriate.

An experienced board member, as a Chair of a user-led disabled people's organisation, Shadow Trustee of a hospice, and former Trustee of a small, rare disease medical research charity for five years. Experience of governance, both charity and for business governance, as an entrepreneur and business owner; overseeing and developing strategy including training in participatory strategic planning, setting goals, aims and key performance indicators and the metrics and milestones by which to measure them against; developing and implementing business planning; embedding user-led organisational structures; leadership; and organisational development, investing in the development of staff members, teams, and volunteers. Committed to equality, diversity, equity, and human

rights, and always working to set a strong, diverse, and inclusive organisational culture that values and respects the varied and unique lived experience of individual members. A strong disability rights, human rights, and patient rights advocate, utilising a rights-based approach to issues and barriers, as well as working to hold systems to account. Respected for work in planning, developing, and facilitating co-production activities and improving practice, developing new co-research approaches, and pioneering digital methods of engagement and leadership to facilitate the involvement of patients, disabled individuals and seldom-heard groups in research, policy, campaigning, and advocacy. A powerful advocate for valuing lived experience as an asset and developing lived experience-led training, including through a new business venture, supported by a grant and award from the Young Innovators Awards Programme. Particular experience and expertise around healthcare and social care, including healthcare advocacy; disability, human and patient rights in healthcare; patient experience; co-production in health; palliative care services, policy and advocacy; patient involvement in quality improvement and transformation; communication; accessibility; autonomy, agency, decision-making, and self-determination; and self-directed support including Personal Health Budgets and social care direct payments.

Achieving success, impact and influence has been hard-won, with great effort, drive, self-discipline, energy, passion, commitment and to an extent, personal sacrifice, overcoming great difficulties to reach the level attained, both as a working-class individual, and as a disabled woman with a life-limiting illness and complex medical needs who was not expected to reach adulthood. This includes many barriers (physical, bureaucratic, and attitudinal), widespread discrimination, low expectations, inequality, ableist systems and attitudes and ill-conceived ideas and preconceived notions of what someone in this position could achieve, with misplaced assumptions that these achievements come from making allowances, lowering of standards and the work of other individuals rather than purely on the merit of the achievements that have been attained through all the work undertaken personally and professionally.

I sit before you today as a proud disabled woman who has defied the odds – medical, personal, and political – to achieve tangible change and impact, having fought for the rights of others; ensured access to the entitlements and basic provisions needed; influencing and changing policy and practice; raising the expectations we hold for disabled individuals; elevating seldom-heard voices; improving equality and equity in public services; and elevating lived experience as an asset and a tool for change and transformation, not an optional extra benefit or as something to conceal.

## **Education:**

**GCSEs** - The King John School (Benfleet, Essex) / Children Support Service home tuition

A\* - Sociology

A - English, Biology, Physics

B - Maths, Chemistry

C - French

Distinction, Distinction - IT

Pass – IT

### **Other education/qualifications/training:**

- City & Guilds Level 2 Award in Independent Advocacy (2018) with Kate Mercer Training/Blackbelt Advocacy
- Support Brokerage Qualification (5 credits at OCN Level 2) with Imagineer Development UK/the National Brokerage Network (2020)
- Group Facilitation Methods (2019) and Participatory Strategic Planning (2020) with ICA UK
- Safeguarding of Vulnerable Adults Level 2 - ProTrainings (2019)
- NHS Peer Leadership Academy (2018) with NHS England and Peoplehub CIC
- Currently pursuing a Level 3 Award in Education and Training
- Committed to my own personal and professional development, undertaking CPD, e-learning, conferences, training days, webinar attendance and significant reading and research as part of self-directed learning.

### **Employment History and Experience:**

*May 2021 – present*

#### **Lived Experience Learning Ltd**

Founder CEO/MD, Lead Trainer

My new startup, supported by the Young Innovators Awards Programme, to develop a lived experience-led training, e-learning, and education business.

Running lived experience-led training for health and social care professionals, third sector professionals, public sector, and civil service professionals and those within other sectors.

Bespoke rights-based, independent living principle-focussed and practical accredited training for people with Personal Health Budgets (PHBs), NHS Continuing Healthcare (NHS CHC), integrated personal budgets (IPBs) and social care personal budgets (PBs) and direct payments (DP), for the staff that work with them.

Individual employer training for those with PHBs, IPBs, PBs, DP and NHS CHC.

Business-to-business work including training on disability and human rights, equity, equality, diversity, and inclusion (EDI), supporting disabled people and people with other lived experiences.

We will also run peer-to-peer training and empowerment for disabled people. Educating them on how to navigate systems, fill out forms, undergo assessments, apply for things, advocate for themselves, etc., as well as personal development and skills training for people with lived experience such as employment skills, campaigning, advocacy, change-making, media commentating, writing and lived experience consultancy training.

*February 2020 – October 2020*

#### **RISE Expo**

Lead for Advocacy and Awareness

Comms, social media, digital marketing, user engagement, lived experience, advocacy.

*October 2019 – July 2021*

#### **Festival Spirit Limited**

Administration, Communications, Marketing and Fundraising Manager (self-employed).

Linked the charity up with new partners with charities such as Pathfinders Neuromuscular Alliance, Together for Short Lives, Disability Arts Online, Muscle Help Foundation, Muscular

Dystrophy UK, individual hospices, Scope, amongst others. I developed a virtual festival from scratch including funding applications, commissioning acts, organising tech, networking, and forming partnerships, bringing on board colleagues from within my network with skills and expertise, sorting out ticketing, and working out logistics to ensure accessibility and inclusion for participants. Improving awareness and visibility of the charity. Securing donations of items from organisations such as bundle bean, with the opportunity for future partnerships. Liaising with other event organisers such as RISE Expo, Dada Fest, horse trials organisers, Festability and others that our charity may be able to support with our specialist accommodation at events. Much stopped due to COVID, but I still achieved a lot for the charity within my role.

*October 2019 – April 2021*

**University of Sheffield**

Research Assistant

Research and co-production, proof reading documents, webinars, copywriting, reviewing accessibility and information aimed at young disabled people and production of resources.

Lead Co-Researcher – Living Life to the Fullest

Project Co-Researcher, Development and Delivery – Youth Employment UK

Project Lead / Co-Researcher – Scope Capital Modelling for Disability Project

Pioneered digital co-production methods including a Facebook group focus group, whereby we had our research participants, added them to a closed, hidden Facebook group, organised for everyone to introduce themselves and then had 5 key questions to ask over 5 days, with co-researchers facilitating more detailed conversation and questioning, and this led to not only great research data but group identity and peer support, to the extent that friendships were made and we were asked to keep the group open for future communication amongst the participants. Continued to utilise my unique co-researcher methods. Able to develop a webinar on accessibility for Youth Employment UK and we developed a resource around accessibility for organisations and employers.

*November 2018 – present*

**Open University** (via the Open University Sexuality Alliance)

Independent Consultant

Project Lead/Manager for “Talking about...sex and relationships: young people speak out”

Project Lead “COVID-19: Vulnerable young people living with life-limiting or life-threatening conditions and their families: A study of the non-intended consequences of epidemic control decisions”

Project management, support with content production, evaluation, and dissemination, running the young people’s advisory group (the “AdversiTeam”)

I was able to pioneer a different way of working with our young people, based out of a Facebook Group and later Messenger group, We had a group of 14-18 young disabled people representing a diverse group of ethnicities, abilities, religions and beliefs, genders, sexualities and gender identities, and included people with mild learning disabilities.

*July 2018 – present*

**Lucy Watts Ltd**

Chief Executive Officer

Independent Advocacy and Support Brokerage

Consultancy, Facilitation, Speaking and Training

Being paid by CCGs and Local Authorities to build care packages, having overseen £950,000 of NHS funding in the last 2 years alone; providing independent advocacy and fighting for people's rights, care, support, funding, entitlements etc. and providing other services as a consultant, facilitator, public speaker and trainer.

*November 2017 – February 2019*

**Worldwide Hospice Palliative Care Alliance**

Independent Consultant (Patient Involvement Consultant)

Running community engagement activities, reviewing charity governance, co-leading awareness, and media activities, running campaigns, supporting the comms team.

**Voluntary Roles:**

*November 2020 – present*

**Pathfinders Neuromuscular Alliance**

Lead Co-Chair (Chair from November 2020, Trustee since October 2020)

I took over as Chair of Pathfinders in November 2020 as voted by the Board. In December 2020 I was joined by a Co-Chair, whom I am mentoring and training as she has no trustee or charity governance experience. My role as Chair/Co-Chair has involved overseeing the charity through the completion of its transition from a user-led condition-specific charity (as DMD Pathfinders) into a pan-neuromuscular condition user-led charity; updating our aims and objects; leading on the development of a new strategy in January 2021 to take into account the charity's expansion of remit and work moving forwards; updating our governance processes and procedures and ensuring we are compliant in all ways; assisting with the development of new policies and the updating of existing policies, many of which needed to be overhauled; connecting with existing trustees to review their role and ensure full commitment to the board, as some trustees had, prior to my joining the charity, not been fulfilling the role as thoroughly as a trustee should; recruiting new trustees and developing a new board structure with some condition-specific representative trustees and other general trustees to ensure representation of condition-specific experiences within the board; and many other things. My role has also involved dealing with some challenging circumstances, particularly relating to an incident with an email about poor performance of a staff member being sent to the staff member rather than our HR advisors, but was able to steer the charity through this error and with full transparency and compliance with relevant legislation, ending amicably with the staff member who, although no longer works for us, continues to be a charity member and work alongside us in a voluntary capacity.

*July 2020 – April 2021*

**NHS England Personalised Care Organisational Development Board**

Member (Patient and Public Voice/Strategic Coproduction Group member)

Overseeing Organisational Development within NHS England's Personalised Care Group.

This included ensuring targets were achieved, overseeing metrics and measurements, ensuring diversity and representation, and looking at staff and team development activities.

*March 2020 – present*

**St Elizabeth Hospice**

Shadow Trustee

Supporting with governance, strategy, business planning, overseeing finances and reserves, overseeing the staff, sitting on various committees including the patient and family services committee, helping the hospice to develop and grow its services and improve the care and support provided to patients and families, supporting departments with transformation and projects, assisting with new policy development, and representing and being an advocate for the hospice.

*December 2019 – present*

**NHS Citizen Advisory Group**

Member – NHS Assembly representative

Supporting the NHS Citizen Advisory Group, updating on the work of the NHS Assembly as a Patient and Public Voice/Lived Experience member, representing the NHS Assembly, and seeking opportunities for collaboration across the patient and public voice individuals, teams and their projects and departments.

*June 2019 – September 2019*

**NHS England Medicine Review Service Specification Board for GP Contracts**

Patient and Public Voice Member/Representative

Overseeing the medicine review service specification for the new GP Contracts and Integrated Care Systems, deciding on priority patient groups for pharmacist-led and GP-led medication reviews for years 1, 2 and 3, looking at the policy and service specification and arrangements, overseeing how this will be implemented and holding other system members to account.

*April 2019 – March 2020*

**NHS England End of Life Commissioning Steering Group**

Member (Patient and Public Voice)

I sat on the End-of-Life Commissioning Steering Group within NHS England, representing the lived experience of people with life-limiting and terminal illness and those needing palliative and end of life care services, looking at the NHS England hospice grant, CCG funding, hospital palliative care teams, community palliative care teams, Macmillan nurses, Marie Curie nurses, developments in the sector, and the support of End-of-Life care teams and services within the NHS.

*March 2019 – present*

**NHS Assembly**

Patient and Public Voice Member

I sit on the NHS Assembly as one of 7 Patient and Public Voice Members, contributing particular elements of expertise around palliative and end of life care, life-limiting conditions, personalised care, Personal Health Budgets, NHS Continuing Healthcare, patient

rights, highly specialised services, rare disease, complex medical needs, young people, transition to adulthood, co-production and patient involvement.

*December 2018 – present*

**NHS England Personalised Care Strategic Coproduction Group**

Member

I sit on the SCG contributing lived experience via strategic co-production activities within NHS England to design personalised care policy, co-production and engagement models, media activities, contribute lived experience to various boards and to spread the word of the work we do.

*November 2017 – present*

**Palliative Care Voices**

I founded palliative care voices as the first international palliative care patient and carer advocacy network, working with support from the WHPCA to champion, campaign for and create an evidence base for involving patients especially, and carers, with lived experience of palliative care in advocacy, campaigning, meetings, policy creation, within all levels organisations, engaged with governance activities, and so on.

*March 2017 – December 2019*

**NHS England Children with Complex Needs and SEND Board**

Member – young people's representative/patient and public voice representative

I sat on the board that held various stakeholders to account around children with complex needs, special educational needs and disability, looking at meeting targets across the NHS, services to support them, EHC plans with respect to health, reviews and audits, the experience of young people and families and how we can improve the care, support and offer for children, young people and families.

*March 2016 – March 2018*

**NICE End of Life Care Guideline Committee (adults)**

Patient and public voice representative

I sat on the NICE End of Life Care for Adults guideline committee and contributed my lived experience and oversaw grading of research, development of the guideline, drafting, professional input and ensuring it was rooted in the real-life experience of people with life-limiting and terminal conditions, and needing palliative, hospice, and end of life care services.

*October 2014-June 2019*

**Pseudo Obstruction Research Trust (PORT)**

Trustee and volunteer

Running the day-to-day elements of the charity including admin, comms and marketing including social media, fundraising coordination, research liaison and research manager

(including putting out research calls, organising scoring meetings, communicating with research project leads that we have funded, ensuring reports are submitted on time etc.), attending events and fundraising directly, speaking engagements, project management including a project I built and led on start to finish on my own, introducing impact reports starting with our 10<sup>th</sup> anniversary impact report, designing graphics and banners, creating the newsletter, creating, designing and writing copy for patient information booklets and packs, organising a Patient Information Day and coordinating and managing the filming of all sessions, and more.

Prior to becoming a Trustee in October 2014, I was a volunteer for the charity for 3 years.

### **Research:**

Living Life to the Fullest – University of Sheffield (2017-2020) [ESRC Funded]

MAGICYL Dignity Therapy – multi-agency bid (2018-present)

DIGNITAL (2020-present) [NIHR funded]

COVID-19: Vulnerable young people living with life-limiting or life-threatening conditions and their families: A study of the non-intended consequences of epidemic control decisions – (2020-2021) [Open University funded]

### **Awards:**

New Year's Honours 2016: appointed MBE for services to young people with disabilities

Master of the University for the Open University (MUniv) in 2018

Fellowship of the Royal Society of Arts (FRSA) January 2019 – present after being invited to apply in recognition of my “commitment to the rights of people with disabilities”

9<sup>th</sup> most influential disabled person in Britain in the Disability Power 100 List 2019 (and listed in the top 100 in 2018 and 2020)

Digital Leader of the Year (2020)

Young Innovators Award (2020/21)

Finalist, Community Spirit, Women of the Future Awards (2019)

Runner-Up Queen's Young Leader (2018)

Top 50 Patient Leader, HSJ Awards (2015)

Jack Petchey Achievement Award (2010)

Diana Award (2010)

### **Memberships:**

Royal Society of Arts

Support Brokerage Network (Imagineer Development UK CIC)

International Association of Facilitators (IAF)

International Association of Hospice and Palliative Care (IAHPC)

Citizen Network

Affiliate Member – iHuman (the Research Institute for the Study of the Human) at the University of Sheffield

People in Partnership Member – Hospice UK

I will soon be joining the Association of Chairs and the Institute of Directors.