Questionnaire UK COVID-19 Inquiry:

Module 2 - Rule 9 Request to John's Campaign Reference: M2/R9R/JC/TJS

Please provide the following information:

1. *A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.*

   Please be aware of our website https://johnscampaign.org.uk/

   Johns Campaign was founded in November 2014 by Nicci Gerrard and Julia Jones as a direct result of the observed deterioration and death of Dr John Gerrard, a man living with dementia, when he was separated from his family support due to an infection situation in hospital. An article in the Observer newspaper[1] triggered one of the biggest reader responses experienced by that paper with support from readers whose loved ones had suffered similarly. They had not usually experienced complete separations due to infection control but the daily structural separations enforced by restricted hospital visiting times had proved hugely detrimental to the wellbeing of many people living with dementia. Damage was usually irreversible.

   The initial focus of the campaign was to change this system of restricted access and ensure that the family carers of people with dementia in hospital were always welcome to support them – at any time of the day or night – if they were willing and able to do so. The campaign gained immediate support from an Adjournment Debate and an Early Day Motion in Parliament (Dec 2014) and support was forthcoming from major charities (such as the Alzheimer's Society), NHS England and the CQC. It was not long before the movement extended to Wales, Scotland and Northern Ireland where all four Chief Nursing Officers and several of the Royal Colleges spoke out in support. As time as passed the need for Johns Campaign principles has also been recognised in care homes, mental health units and other institutions where a vulnerable individual risks being denied the support of the person who knows them best and whose expertise should be used for their benefit.

   John's Campaign has brought about a genuine change in the culture of care for patients with dementia in hospitals. In early 2017 it extended its work to the care home sector. The driving principle remained the same – focusing attention on the right and the needs of those with dementia to maintain their relationships with their families and friends.

   In 2017 Julia was commissioned by Care England to write *Honoured Guests* a guide for managers recommending how to involve family carers[2] and in 2019 she began working with an informal care home steering group, which shared good practice welcoming and involving family carers in the care home communities.[3] In February 2020, support from Age UK's Malnutrition Task Force brought a larger group of professionals and family carers together for the publication of the

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[1] https://www.theguardian.com/society/2014/nov/29/nicci-gerrard-father-dementia-hospital-care-elderly

[2] www.careengland.org.uk/sites/careengland/files/downloads/Honoured%20Guests%20final.pdf

[3] See for example: https://www.independentliving.co.uk/industry-news/johns-campaign/?utm_sq=g1651ha01e; https://johnscampaign.org.uk/#/post/residential-care-providers-meeting-first-report

booklet *Implementing John's Campaign in Residential Care.*[4] Our website became a hub of good practice for care homes as well as for hospitals.

When dementia is understood as a disability (which it is) people living with that condition have undeniable need for their regular carer, with expert person-centred knowledge, to benefit from hospital treatment, just as a physically disabled person would have undeniable need of a wheelchair or a non-English speaker an interpreter. For most of its existence Johns Campaign has accepted voluntary pledges from hospitals (and other institutions) to welcome carers whenever the patient (or resident or service user needed them). These pledges are recorded on our own website and on a list held by the Observer newspaper[5].

In fact we now consider that this welcome to carers should be part of a hospitals duty (and the duty of all public organisations). These 'reasonable adjustments' are those required by Equality legislation (expressed for instance in the NHS Constitution). Such an unequivocal welcome to family carers in support of a patients / residents /service users choices and wellbeing is also in line with the several other pieces of legislation.

Some institutions managed to adhere to their Johns Campaign pledges though the pandemic and there was some support from both NHS England and Scotland for them to do so. Most however did not. We now campaign for a legal right to a personal care supporter which should be attached to each individual not to the health and social care institutions. Their duty should be to facilitate this for the benefit of their vulnerable patient / resident / service user.

Johns Campaign is purely voluntary and has no staff and no funding. It is best considered as a movement as it works though the goodwill and understanding of others. This is both a strength and a limitation.

2. *A brief description of the group(s) which the organisation or body supports or represents.*

John's Campaign supports vulnerable people and their families when the person in need of support is being accommodated in any of the institutions of the UK health and social care system. It has a particular focus on people living with dementia but has learned the truth of the saying 'get it right for dementia and you get it right for everyone'.

It is perhaps worth noting that both Nicci Gerrard and Julia Jones have published books on the understanding and best management of dementia. Nicci's, in particular, has been widely read and admired not just in the UK but abroad. Her personal research, understanding and expertise should have given her a place in any serious consideration of the effects of separation on people with this condition. In 2016, Nicci won the Orwell Prize for Journalism for her articles about dementia, and her book *What Dementia Teaches Us About Love* (March 2019). She is a patron of Suffolk Family Carers, a patron of Creative Dementia Arts Network, and is on the Royal College of Psychiatrists National Audit for Dementia steering group.

Julia Jones became an 'expert by experience' through her 'primary carer' relationship with her mother June who lived with mixed dementia and mental health problems and died in December

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[4] Ibid.

[5] https://johnscampaign.org.uk/participants

2018 aged 94 in a care home. She expressed some of her ideas in *Beloved Old Age and What to Do About it* (2016). She is currently on the NHS England Advisory Board for Care Partner policy. Pre-pandemic both Nicci and Julia had travelled to all parts of the UK by invitation to address health and social care professionals on the benefits of welcoming family carers.

3. *A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.*

From March 2020 we warned as consistently and publicly as we could about the real dangers of imposed separation particularly for people with dementia or other cognitive impairment. Because of our extreme structural limitation (two volunteers and a website manager) events led us to focus most of our campaigning attention on care home residents in England (and to a lesser extent Wales) though we did not lose touch with the hospital sector in England and did our best to respond to pleas for help wherever we received them.

As an un-funded organisation whose only concern was the welfare of vulnerable people in health and social care institutions we believed that we could have been trusted to represent health and social care users with honesty and transparency. However, the consistent refusal of the Department of Health and Social Care (DHSC), in particular, to engage in any form of dialogue or appear to consider the impact of their actions on the most vulnerable people eventually persuaded us to crowdfund and take legal action specifically against Government guidance of visiting in and out of English care homes. This appeared to be effective as the DHSC on each occasion withdrew and amended their documents. But what a waste of time and effort when such conflicts could have been resolved by respectful discussion. We constantly offered to talk and to share our unique knowledge gleaned over the previous years of effecting positive change. One unanticipated benefit was that the employment of legal advisers also made it possible to issue a series of 'Guides to the Guidance' which many individuals found very helpful as they fought their own battles for access to key family members.[6]

We used our personal links with both providers and charities to share our concerns and offer consensus approaches whenever possible.

John's Campaign has an informal network of NHS Ambassadors and also a Care Home Providers group who had worked together to co-produce a booklet on family carer involvement in February 2020 – which included work on balancing infection prevention and the maintenance of individual well being. Quite often we were able to speak for both NHS and social care providers who were not able to voice their concerns publicly. We also undertook some surveys and worked together with other concerned organisations eg in One Dementia Voice, Five Nations Care home forum and increasingly closely with the Relatives and Residents association and with Rights for Residents.[7] As the pandemic progressed we increasingly found ourselves advocating for groups

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[6] See for example: https://johnscampaign.org.uk/post/how-to-visiting-guide-for-care-homes

[7] See for example: https://www.tide.uk.net/one-dementia-voice ; https://www.dementiauk.org/one-dementia-voice-care-home-visitors/ ; https://johnscampaign.org.uk/post/the-grim-truth-behind-the-governments-fine-words

such as young learning disabled people and those with multiple profound disabilities, not necessarily cognitive.

4. *A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.*

   We have contributed constantly to article and reports in national newspapers, on TV and radio both in our own persons and also by putting programme makers in touch with people directly impacted by official guidance. We have felt consistently disappointed and angry at the refusal of the DHSC to engage in any dialogue but have always responded to requests from organisations such as the Joint Committee for Human Rights and (occasionally) the CQC. We have a very active social media presence on both Facebook and Twitter and have done our best to use this to inform, support and respond.

   We have consistently offered case studies as evidence (including as part of our judicial review challenges) and have worked closely with relevant other organisations and also with experts (several witness statements were filed in support of our judicial review challenges). Our website has continually contained the eloquent testimony of individuals and we have done our best to share this with those who have the power to make change.

   Our booklet The Holding Pen[8] explored the cruel impact of enforced 14 day isolations on people without the capacity to understand.

   Our report Midsummer Milestones[9] was an attempt to highlight for the new Secretary of State the gulf between conditions for people in residential care and the rest of the population and also to share our understanding of the unlawful actions being condoned.

5. *The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.*

   No.

6. *Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or*

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[8] https://johnscampaign.org.uk/book/the-holding-pen

[9] https://johnscampaign.org.uk/book/midsummer-milestones

with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.

Yes – mainly with the English DHSC. Initially we sought engagement from the DHSC without turning to lawyers. For example, on 10 July 2020, One Dementia Voice sent a letter to the Secretary of State for Health and Social Care calling on him to act urgently and describing what was happening in care homes due to visiting restrictions as a "hidden catastrophe". In particular, we sought the designation of family and friend carers as "Key Workers" so that they could be subject to the same testing regime as care home staff and could resume their roles fulfilling the essential care needs of residents. To date we have not received a response to that letter.

We therefore felt that we had no alternative but to approach lawyers to see whether there was any way of bringing a legal challenge to the Government's guidance on visiting arrangements and we instructed Leigh Day solicitors who entered into pre action correspondence focusing on visits into care homes on our behalf on 9 September 2020.

We engaged in extensive pre-action correspondence in advance of both of the judicial review challenges brought against the Secretary of State for Health and Social Care. We were also collecting evidence and offering it to the DHSC (including through examples in letters, and in public statements) to show not only impact but also seeking to influence decisions on future action. Between our judicial review challenges we consistently wrote to the DHSC raising various concerns about different iterations of guidance and seeking round-table meetings. We were consistently refused (on the basis that they would not engage with us whilst legal correspondence was ongoing) and guidance was often updated belatedly and without taking all factors put to the DHSC into account.

7. *A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.*

(i) We think that laws such as the Equality Act, the Care Act, the Mental Capacity Act and Human Rights legislation are there for a good purpose and that public authorities should be obliged to consider and respect them at all times. We were shocked by Equality Impact Assessments that showed clearly the disproportionate damage that would be inflicted by enforced separations but which were ignored.

(ii) We believe that respect for individual dignity and responsibility should always be maintained and that infection control should not be allowed to override personal consent and also family responsibilities such as guidance and power of attorney should be respected, especially when decisions are being taken which affect both quality and quantity of life.

(iii) Very much more attention should be paid to consulting with people who speak for those who will be most directly affected by interventions such as compulsory separation, distancing, mask-wearing, enforced isolation and confinement, deprivation of liberty and who cannot easily speak for themselves. It is not good enough only to consult provider organisations whose priorities are necessarily different in important respects.