It is a great privilege and pleasure to have been invited here to Bologna to help celebrate the life and work of Alessandro Liberati in this special meeting with its unusual structure and approach. I like to think that he would have been pleased that the meeting would begin with a few thoughts from someone who became an Independent Citizen Advocate for Quality in Research and Healthcare as a result of a similar frustrations to his own on becoming a patient, concerning unavailability of proper information coupled with poor quality research that failed to consider its relevance to its prospective participants and their need `to know’.1

Alessandro had always called for a more inclusive inter-disciplinary approach that included patient and citizen participation in research and healthcare,2 evident when he set up the Italian Cochrane Centre in 1994. This was a decade before his ‘Damascus Road’ moment, when he wrote about his unfinished trip through uncertainties in 2004, vividly describing his sudden transition from a `subjectively healthy man to a potentially ill person with considerable anxiety’3 and his frustrations about the scrappy, difficult to find, largely unpublished `evidence’ for treating his serious and unusual condition.

He wrote that there were two lessons he learned first-hand as a patient himself. Firstly, the experience reinforced his strong beliefs about the best way to go about research and the provision of healthcare, but it prompted a flood of questions. He lamented: `How far can we tolerate the butterfly behaviour of researchers, moving on to the next flower well before the previous one has been fully exploited?’ He said that the first lesson he learned was `that as a patient I felt even more strongly about what I've been fighting for throughout my career’, asking `why was I forced to make my decision knowing that information was somewhere but not available?’

And the second lesson he learned was that his `desire to participate in decisions was stronger than ever’. For him, with his experienced research background, his particular desire at that time was to be able to properly participate in decisions about how his condition might be treated.

For me, as an ordinary research-naive citizen at the time of my diagnosis of screen-detected ductal carcinoma in situ of the breast (DCIS) in 1991, unable to make a reasoned decision about being a participant in a trial because of poor information content and quality, my blossoming desire was to be able to participate actively in decisions about formulating the research question itself so that it might better reflect what prospective
participants like me might want as an outcome, and to participate in contributing to
decisions about the kind of information they would need if they were to have a better
chance of making a satisfactory and satisfying decision.

This intense dilemma then led me to step back in time, to my earlier decision to attend for
breast screening. And with it came the illuminating realisation that it had been a very ill-
informed decision for the same reason: poor quality information! My battle for citizens
to have good quality information about screening when they are approached by health
professionals has continued for 20 years, intensifying recently, following publication and
coverage of the Marmot Review of breast screening.

The personality of Alessandro shines through like a beacon in his cri de coeur in the
BMJ. His ability to communicate directly, openly and passionately with all people, is
such that we are drawn to empathize with his anguish about the uncertainties and
inadequacies he encountered as a patient, as the touching and heartfelt rapid responses to
that paper clearly testify. For him, there is no hiding behind use of passive, impersonal
third-person plural tenses in his writing: simply and clearly he directly engages us
individually in the ‘first person singular’! It is not only a cri de coeur, but a strong
rallying call to action for us to join with him to remedy insufficiencies. Who could resist!
Alessandro is fondly remembered as much for his character and attributes as for his work
contribution: but, of course, as we can see from this illustration, these two things are
inextricably linked.

Calvino’s concepts
By considering the concepts of lightness, quickness, exactitude, visibility, multiplicity and
consistency, as explored by Italo Calvino is his Six Memos for the Next Millennium,
between us we shall not only be able to look back to consider how Alessandro
exemplified these in his professional life, but also to consider how we might, in good,
lively and varied company - as did John Bunyon in his Pilgrim’s Progress - continue our
pilgrimage towards ‘the shining light’, to use them to shape what we do now and how
we go about it, warmed by the remembrance of his light touch and clear vision for
achieving better care for all citizens and patients. As we can see from that
autobiographical account of his illness from its first manifestation, what mattered most to
him was the quality of care, achieved by means of well-communicating, collaborative
inter-relationships of all those involved, inspiring us to strive for mutual understanding
by working together to search for better ways of doing everything related to providing
that quality of care.

Building structures; building on history
I like to imagine his vision for healthcare research activity as the building of a strong,
light framework: an all-inclusive, welcoming structure with many rooms opening into an
airy atrium. Topics of public concern would be deliberated in this forum; uncertainties
exposed; business transacted; and justice dispensed. The whole complex would be light
and airy; kept clean of all rubbish, unnecessary fixtures and dark, dead wood; flexible in
design, allowing modifications or additions as their need became apparent. Access and
navigation to all parts would be well signposted. The community’s regulation and
governance would be kept to an essential minimum, formulated always with an eye to achieving the aim of providing timely, robust and reliable evidence to guide doctor and patient or citizen together as they sought to make healthcare decisions, be it individually or for a population. Equity, justice and truth – dispensed with mercy - would be its guiding principles in the search there for better ways of doing things.

His structure would be the antithesis of the city of Hypatia in Italo Calvino’s account of Marco Polo trying to find the Sage in *Invisible Cities*. Feeling cheated, the traveller decides to demand justice of the Sultan – but could only question the Philosopher. Entering the great library in his search for the Sage, he became lost amongst shelves collapsing under the [weight] of the vellum bindings. He followed the alphabetical order of vanished alphabets, up and down halls, stairs, and bridges. But the Sage was found to be sitting on the lawn in the garden in amongst the children’s games.

The very visible cities of Bologna and Padova are the earliest seats of learning in Italy: Bologna, the ‘nourishing mother of studies’ founded in 1088, and Padova, pre-existing 1222. Perhaps one could conjecture that both Italo Calvino and Alessandro Liberati have been well-nourished by this weighty anchorage of an inspired legacy of culture and learning? Their considerable legacies in literature and medical research build on that foundation, providing us with clear directions to shape the values of the future into this new millennium, not forgetting the past.

And, seven centuries on, still visible for us all to contemplate in Padova, are the Giotto frescoes, illuminated by his blue starlit sky in the Scrovegni Chapel, some depicting the seven virtues of prudence; fortitude; temperance; justice; faith; charity; and hope: with human emotions plain to be seen. Compassion and values clearly and beautifully depicted!

Also to be found in Padova, and more attractive than dry dusty tomes on collapsing weighty shelves in dark dusty libraries, is the world’s oldest existing botanical academic garden, where students there can learn (like Italo Calvino’s Philosopher in *Invisible Cities*) in the light outside in the garden. It was created in 1545: its exceptional structure - which is of high scientific interest - and its main scientific and architectural features, have been preserved for us to enjoy. This beautiful structure represents the birth of science, of scientific exchanges, and of the awareness of the relationship between nature and culture. Its creation made a big contribution to the development of many modern scientific disciplines, notably botany, medicine, chemistry, ecology, and pharmacy. It also has great scientific interest in terms of experimentation, educational activity and botany collecting. The uniqueness of the architectural features have made it a model for similar institutions elsewhere in Italy and in the world. The Senate of the Venetian Republic approved the foundation of this complex for the cultivation of medicinal plants: it is of extraordinary scientific, historic, artistic and naturalistic value.

This is part of the wonderful Italian heritage that surely nourished the spirit of Alessandro Liberati and Italo Calvino.
Virtues and values
Just as Italo Calvino sought to do in the Charles Eliot Norton lectures he was due to deliver at Harvard in 1985-6, exploring the concepts of **Lightness, Quickness, Multiplicity, Exactitude, Visibility** and **Consistency**, here we are trying to throw light on the virtues that Alessandro possessed and brought to his work, in order that we can attempt to emulate him to better shape the values of the future. Our individual memories are unique, and will be different. But we have collectively been charged to use these five concepts **to evoke the spirit represented by his life, to make visible the values that sustained his thoughts and actions** and **to give all of us a way to reflect on it, questioning ourselves about the meaning of being researchers within the world of healthcare, of our being “technicians” dealing with such delicate issues for people’s lives**.

Conduct or competence? Covenant or contract? Society or State? Heart and Head?
Sadly, the technical aspects of healthcare multiply, increasingly intrude and monopolize. Heavy-handed regulation, concentrating on judging doctors’ competence (with little consideration for conduct), is evidently thought by UK policymakers to be the way to weed out the ‘failures’ and produce ‘better doctors’ It is based on the premise that doctors are fit to practice if it is proven every five years that their knowledge is up-to-date. Policymakers concentrate on competencies, neglecting conduct; they consider contracts rather than cultivate covenants; they seek to strengthen State, rather than serve Society. Our government health secretary, Jeremy Hunt, speaking about revalidation, is reported to have said: “Doctors save lives every day, and making sure they are up to speed with the latest treatments and technologies will help them save even more. This is why a proper system of revalidation is so important.” No one would deny that patient safety is important, but I find it alarming just how much clinical practice and public health medicine today seems to have ‘saving lives’ as its main goal, regardless of the collateral damage it creates as it does so, with its ‘friendly fire’, using the weightiest ammunition to extend life regardless of the heavy costs of doing so. That ‘more is not necessarily better’ is increasingly being considered: we must dare to think about doing less, adopting a lighter touch – advocate for less ‘early detection’; less weighty treatment.

We are told by Calvino’s widow, Esther, that when he was thinking about the **vast range of possibilities that were open to him, he worried, believing as he did in the importance of constraints**. There are certainly restricting conditions when delivering a talk, or in writing a paper, or in undertaking research, or in writing a research report, with respect to time and length of content, but constraint can constitute a necessary discipline for more satisfactorily achieving a pre-defined, useful outcome. It can force us to jettison unwanted matter; to travel lightly. Constraint’s close cousin, restraint, in the sense of artistic control, or reticence, can also contribute to achieving a powerful lightness, perhaps at times through understatement. Paradoxically, we are less inclined to take note of loud people who throw their weight about in the belief that we shall be more inclined to listen to them, than those rare but easily recognizable people with a light touch, a gentle manner, possessing quiet authority that is neither arrogant nor overly-humble, but speaks – human being to human being (whether one-to-one, or in a crowd) – as Alessandro could.
I am also reminded of my favourite Choral Director, Lazlo Heltay, who magically trained and inspired the Windsor Festival Choir with precise direction in a voice sometimes no louder than a whisper, in Eton college School Hall. I shall never forget his direction of rehearsals of Haydn’s *Creation*, with its choral depiction of the creation of light, where, after representation of chaos, and after a pianissimo passage full of suspense and anticipation, there is the sudden explosion of the surprise fortissimo brilliant C major chord on the word *Licht* (Light).

So, also, with Alessandro – I never heard him raise his voice. I loved his light and gentle approach: he seemed to me, as he reminisced, to be able to hover above the whole scene, touching lightly on this and that aspect, not overlooking any part that went to make the whole: weaving aspirations, calling for sound ethical standards, or making pleas for less arrogance amongst the weightier considerations of such things, for example, as systems for improving reporting standards (PRISMA) in his call to arms. How could one fail to respond to his gentle exhortations?

Gerd Antes speaks of a man who “was always friendly and open” and who “in the same moment could be cheerful and light-hearted, but also serious.” His honesty, humanity and insightfulness were noted by the Italian Minister of Health, Renato Balduzzi. Quality in general, and quality of life in particular, were prime concerns for Alessandro.

**Lightness**

So I am glad to have been given *lightness* to consider, both in respect of Alessandro’s approach, and in order to suggest some ideas about how *lightness* might help shape health research in the future. On being invited to give this talk, my first thought was to think about *lightness* as opposed to *darkness*. But then I found that Calvino’s inspiring essay began with the words ‘I will devote my first lecture to the opposition between *lightness* and *weight*, and will uphold the values of *lightness*.’ He continues ‘This does not mean that I consider the virtues of *weight* any less compelling, but simply that I have more to say about *lightness*.’

May we continue to benefit from the legacy of Alessandro’s light touch!

©

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Rowhedge, Colchester, UK.
28th November 2012

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