Children and Young People's Health Outcomes Forum
Report for the Secretary of State for Health

Response to the Francis inquiry report

1. Introduction

This is a response from the Children and Young People's Health Outcomes Forum to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry by Robert Francis QC (2013)[1]. We have additionally considered the subsequent associated reports by Sir Bruce Keogh[2] and Professor Don Berwick[3].

We focus on a number of key themes where the Forum believes an additional response is essential to address the particular needs of children and young people. These are

- a culture that supports a child and young person focused approach, with the involvement of children and young people in their own care
- leadership at all levels to advocate for, and support, the needs of children and young people
- workforce capacity and competence, and
- specific issues of patient safety that are most relevant to children and young people.

First and foremost is culture, which is not only a driver but a precondition for good care and the safety of children and young people. All the other aspects we consider are dependent upon it. Our recommendations focus on what we understand to be important for children, young people and their families, for organisations, and for staff who work with children and young people. That understanding is informed by work the National Children's Bureau have done on our behalf over the summer to seek the views of children and young people, in order to ensure we have captured what they want and expect.

We note with interest that, in the timeline of events at Mid Staffordshire, two adverse external assessments in 2006 demonstrated that children's services were amongst the first markers of problems in that organisation. Our response, whilst based on the recommendations that Robert Francis makes, draws parallels and applies equally to other nationally significant cases relating to children and young people's services in recent years, such as Beverley Allitt[4], cardiac surgery at Bristol[5], Victoria Climbié[6], the Redfern report into events at Alder Hey[7], and Peter Connelly[8].

These examples represent different parts of the health and care system used by children and young people. They variously demonstrate a lack of leadership, a failure to hear children and young people's voices, a workforce lacking in relevant skills and compassion, a systemic lack of candour, and insufficient regard for or assessment of children's safety.

The appalling circumstances that provoked the Winterbourne View review and report[9] also addressed much of this territory, and whilst that report focused on the residents in Winterbourne View, who were adults, the Department of Health has rightly recognised that the work programme to address the deficits in care needs to be extended to children and young people with learning disabilities.

The Children and Young People's Health Outcomes Forum was set up by the then Secretary of State for Health in 2012 to identify the health outcomes that matter most for children and young people, and how improvement in these could be delivered.

In setting out the Forum's findings[10], we concluded, *"it is becoming increasingly evident that health outcomes for children and young people in our country are poor. This is not what most people believe. There is a general sense that healthcare is good, that we care about our children and that the outcomes are at least comparable with other countries. The system and country appears to be both sentimental and complacent."* In its report, the Forum identified effective leadership, a child and young people-focused culture, capable staff and safe services as fundamental to the delivery of good health outcomes.

The Forum reported in July 2012. In February 2013, alongside a system wide response to that report[11], the Department of Health and partner organisations signed up to and published a Pledge[12] with a shared commitment to improving the health outcomes of our children and young people, so that they become amongst the best in the world.

2. Culture – that supports a child and young person focused approach, with the involvement of children and young people in their own care

In its first report, the Forum advocated "child friendly health care" – a universal children and young people friendly culture of care across the whole system, providing the essential underpinning for the provision of excellent care for children, young people and their families in all settings.

In his recent report on *Improving the Safety of Patients in England*[13], Professor Don Berwick calls for the NHS to become a learning organisation, "a system devoted to continual learning and improvement of patient care", with four guiding principles:

- placing the quality of patient care, especially patient safety, above all other aims
- engaging, empowering and hearing patients and carers throughout the entire system and at all times
- fostering whole-heartedly the growth and development of staff, including their ability and support to improve the processes in which they work
- embracing transparency unequivocally and everywhere, in the service of accountability, trust, and the growth of knowledge.

The Forum fully endorses this vision, which reflects our previous recommendations. These principles should underpin all services that the NHS provides, including those for children and young people. However, as we, and others[14] have previously identified, the experience of and direct feedback from children, young people and their families is that the NHS does not explicitly recognise or meet their specific needs. We are clear that if the NHS is to improve quality and outcomes for children and young people then these needs must be considered.

But we must go further than that. In order truly to improve outcomes, we need a culture for children and young people that is shared by the *whole system* – in a continuum across health, social care, education and the voluntary and independent sectors. Wherever they receive health care, children and young people should be treated in the same way, in a "universal culture" which considers their needs, listens to them and puts them first; a culture of openness, transparency and candour; strong leadership, working to agreed standards, and better handling of complaints.

The NHS Constitution[15] provides the basis for the inclusion of these cultural values for children and young people within the health service. In its first report, the Forum recommended that *the revised NHS Constitution is drafted in such a way as to be applicable*

to all children, young people and their families[16]. This remains essential if the NHS is to meet their needs. **We further recommend that, when it is refreshed, the Constitution should make appropriate reference to age-appropriate care, the importance of which we highlighted in our first report.**

The Forum also made explicit reference to the need for all organisations in the health and care system – providers, commissioners, arm's length bodies, regulators, local authorities and patient voice organisations – clearly to set out their aims and ambitions for children and young people. Robert Francis too makes it clear that cultural responsibility extends across all these bodies. For cultural change to be relevant for children and young people there needs to be a tangible shift. Adopting the values of a children and young people friendly culture across all agencies would start to create a practical agenda for change at policy making, commissioning, delivery and regulatory levels.

This culture is one which puts the child or young person first, exhibited through the whole system of health, education and social care by

- involving them in meaningful engagement in decisions about themselves, including consent to treatment – and providing them with a voice
- considering them as whole beings, not as a part needing attention
- recognising the importance of their family
- treating them in age and stage appropriate environments (i.e. infants, children and young people appropriate), and
- seeing the child and young person in the context of their family and the community in which they live.

The key elements of a children and young people friendly culture are

- participation of children and young people and their families – in individual decisions, in service improvement and policy/priority setting

- prevention and proactive care at every level – primary, secondary and tertiary

- integrated provision based on pathways that make sense to children and families – essential to assist them to navigate increasingly complex and fragmented services across all sectors.

Participation, prevention and provision based on pathways are recurring themes in the UN Convention on the Rights of the Child (UN CRC)[17]. They are also central to the NHS Constitution.

Participation is well established in the adult world, where user groups have a voice in the commissioning process, but it remains an undeveloped concept in the world of commissioning and providing children's services.

Provision based on pathways is at the heart of network development, promoted in the Forum's first report. We welcome that in response to one of our recommendations in that report[18], NHS England has launched the Strategic Clinical Network for Maternity and Children's Services as one of four areas requiring strategic development in order to improve outcomes.

We have been heartened by the widespread positive and open response to our first report and the commitment of nearly all organisations to the system wide Pledge published in February 2013. However, a notable exception to this commitment was Monitor. We trust

Monitor will rethink this position in order to demonstrate its commitment to improving outcomes for children and young people and to recognise explicitly their identifiably different needs.

The position of children and young people in society rarely provides them with a strong and effective 'voice'. They experience a lack of engagement within services, and really struggle to get their voices heard and to be involved in decisions about their own health. This makes it difficult for them to take responsibility for their treatment and care. Children and young people know what needs to be done to improve the services they use – they told us that where health outcomes are better, it is because they and their families are involved in decisions about their care, having received relevant and age-appropriate information, and that care is provided in environments appropriate for their age. Their voices must be heard and responded to consistently throughout the health system.

The Forum therefore recommended in its first report that *all health organisations must demonstrate how they have listened to the voice of children and young people, and how this will improve their health outcomes*[19]. The Pledge published in response helpfully also articulates a shared ambition that children, young people and their families will be at the heart of decision making, with the health outcomes that matter most to them taking priority[20].

To ensure children and young people are being listened to, we also reiterate the recommendation in our first report that *the Department of Health and NHS England should incorporate the views of children and young people into existing national patient surveys and develop surveys for children and young people in all care settings as a matter of priority*[21]. These surveys must cover the issues that are of importance to children and young people.

We further recommend that, in every children and young people service, there should be children and young people identified to act as ambassadors for their peers. Their role would be actively to encourage their peers to participate in changing services across the whole system, including health, social care and education. If this approach were adopted, children and young people could ultimately become confident drivers of change. The Forum will work up this proposal further with the help of children and young people.

Similarly, the Forum recommends that all organisations that commission or provide children and young people's care develop a facilitated constituency of children and young people, from which representatives should participate in the governing body. There should also be formal roles in Healthwatch for children and young people.

We welcome as well the proposed establishment by NHS England of a Children and Young People's Forum. This would establish both a children and young people's advisory and action group for NHS England, and a national network of young healthcare champions to participate in developing national health policy and to deliver action and change on specific programmes of work.

Robert Francis emphasises the need for openness, transparency and candour, particularly when something goes wrong in the delivery of care. We strongly support his recommendations but wish to stress the importance of being inclusive of children and young people. In the same way as adults, children should be involved if errors are made or if harm occurs to them as a consequence of care or treatment. Information needs to be delivered in an age or developmentally appropriate manner, in the vast majority of situations with the support and involvement of their families. Children and young people should similarly be enabled to participate in any investigative process and in the response to complaints. We also share Professor Berwick's caution about inducing defensive practice and bureaucratic

overload if every case of error that does not cause harm or near miss is reported to patients, and the need to develop a balanced approach to proactive disclosure.

We recommend that, where direct error occurs or harm ensues to a child or young person as part of their treatment or pathway of care, the organisation concerned must be able to demonstrate that it has fully and appropriately informed and included the affected child or young person in its investigation and response.

3. Leadership – at all levels to advocate for, and support the needs of children and young people

Many of the issues regarding culture in the Francis report led back to the style of leadership in the organisation – forceful styles of management, a lack of openness, denial and defensiveness, a lack of appreciation of risks for patients and too great an emphasis on targets. The result was patients fearful of upsetting staff, clinician disengagement, low staff morale and an acceptance of poor standards of conduct. Many of these findings are similar to those previously reported in inquiries relating to children and young people.

Professor Charles Vincent, in his evidence to Robert Francis, said "maintaining a safety culture, indeed any kind of culture, requires leadership and on-going work and commitment from everyone concerned".

The Mid Staffordshire Public Inquiry report, which took account of the local children's service reviews in 2006, highlighted it was unclear who followed up reports and implemented remedial action plans. Boards have a significant leadership role in monitoring services, receiving feedback from users and ensuring the learning from incidents and complaints is disseminated and acted upon. Key findings relevant to all children's services, not just in Mid Staffordshire, were the negative culture, the disengagement of professionals, the ignoring of patients and the lack of Board governance. Boards therefore also have an important responsibility to role model the values of the NHS and to develop an encouraging, supportive and enabling culture for their staff.

Robert Francis suggests that two of the requirements for a universal culture in which the patient is the priority are freely available and full information on attainment of the values and standards, and a tool or methodology such as a "cultural barometer" to measure the cultural health of all parts of the system. In his Mortality Review report[22], Sir Bruce Keogh states that Boards must know that they have people with specific expertise who are able to identify the correct data and know how to scrutinise it in order to drive improvements.

We endorse these recommendations and additionally wish to emphasise the need to consider children and young people. Boards must have a means of assessing and monitoring the culture of their organisation. **We recommend that any "cultural barometer" or other similar tool in use or under development is reviewed to ensure that it picks up the specific needs of children and young people.**

Too often, in organisations that have their main focus on adults, the culture and leadership is not geared to children and young people or the professionals who work with them. This can have a detrimental effect on individual staff and on teams.

In our report of July 2012, the Forum identified the importance of leadership for children and young people *at every level* within the health system and accordingly made a number of recommendations. In this response we wish to reiterate and extend this.

We therefore recommend that every organisation that provides, commissions, or regulates services for children and young people – including those whose services are predominantly adult-based – should have named executive and non-executive leadership for children at Board level. They will be accountable for ensuring that children and young people in that organisation's care receive high quality, evidence based care and are seen in appropriate environments, with the right staff, who share the same vision, values and expected behaviours. People at all levels need to exercise leadership and take responsibility for how care is provided – and everyone needs to be "pointing in the same direction".

The Forum recognises the important leadership roles that both commissioners and regulators have in driving change. Sir Bruce Keogh recommends[23] that patients and clinicians should become more involved in Care Quality Commission inspections. This needs to include children and young people. We are encouraged by early indications from CQC that children and young people and professionals who look after them will, indeed, be included in inspections. However, we fully share Professor Berwick's view[24] that "achieving a vastly safer NHS will depend far more on major cultural change than on a new regulatory regime".

It is imperative that leaders are able to lead by example, and promote a sense of pride and optimism to boost staff morale. In particular, we emphasise the importance of encouragement, enablement and practical support of staff to provide them with the confidence to make sound judgements, to be open to suggestions from children, young people and families and to provide them with timely information so they feel able to take greater responsibility if they wish.

In 2008 the NHS, in conjunction with the key trade unions, the Healthcare Commission and the Academy of Medical Royal Colleges, carried out a major piece of research[25], including interviews with staff from fifty NHS Trusts and a range of GP practices. This research found staff commitment, engagement and productivity was strongly linked to four themes: the resources to deliver quality care, the support to do a good job, a worthwhile job that offers the chance to develop and the opportunity to improve team working.

This and other evidence links organisational culture to the quality of care delivery. Importantly, it is increasingly recognised that if staff are shown respect and trust by leaders in their organisation, and are encouraged and enabled to look at ways to improve their practice, compassionate, dignified care is more likely to be provided.

4. Workforce capacity and competence

As the Forum pointed out in its first report, one of the most important reasons why children and young people's health outcomes are poor in so many areas is that too many staff are still not adequately skilled, and do not have sufficient training in children and young people's physical and mental health to enable them to undertake their work safely and well. Some staff have training only in adult healthcare.

All those working with children and young people should have the right knowledge and skills to meet their specific needs – wherever they are in the health system. All professionals providing services for children and families must be "culturally competent" as well as professionally competent. These core skills need to be incorporated into training and education for those working with children and young people.

Children, young people and their families have told us they wish to access high quality, evidence based safe care and treatment, as close to home as possible. Children and young people also told us[26] the importance of the following themes which have particular relevance to workforce development:

- care by professionals who have had training in working with children and young people
- their concerns that general practice and transition from children's to adult services do not meet their needs
- health staff to show respect to children and young people and recognition of their right to be involved in decisions about their health and care
- care to be delivered by competent professionals who communicate well with children and young people and take a joined up approach to their care.

Those with responsibility for workforce development must recognise the importance of what children and young people say about the services they want. We are pleased that in the system response to the Forum's first report, Health Education England (HEE) has undertaken to fulfil a number of the Forum's key recommendations, including selecting a lead Local Education and Training Board (LETB) for the children's workforce. **We recommend that HEE takes full account of our first report and this response in developing its future workforce strategy for children and young people.** Key areas for action include the actual selection of a lead LETB and implementation of our recommendations for improving general practice.

The Francis report has placed renewed emphasis on listening and understanding as a key 'cultural' component. More broadly, central to cultural competence is participation – which includes the ability of staff to listen carefully, communicate clearly and jointly make decisions with children, young people of all ages and their families.

It is particularly important that all staff likely to have "first contact" with children and young people understand the care culture in children and young people services and have the relevant clinical knowledge, skills and competence. This may require enhancing existing skills for some groups of professionals, for example GP and primary care staff including Out of Hours. Or it might mean the employment of children's nurses in advanced practice roles, community children's nurses based in GP practices or the up skilling of school nurses and practice nurses who are not from a children's nursing background.

To ensure that staff focus their attention on the needs of children (including babies) and young people, and can implement the essential components of a child friendly culture, the following should be recognised as core knowledge, skills and competence[27]:

- make every contact with children and young people count – using every opportunity to talk with them about their health and wellbeing, and the choices they may make

- support parents and families to access health promoting services and to make the best choices for their child, building on strengths within the family unit

- share information across pathways, with other agencies and with children and young people

- analyse and evaluate best evidence to inform judgements, decision-making, service planning, commissioning, processes and systems to promote health, reduce illness or the potential for harm and complications arising from intervention or hospitalisation (i.e. medication errors or hospital acquired infection)

- lead, develop and participate in continuous learning from feedback from children and young people.

There must be sufficient undergraduate and post-graduate education programmes to ensure the workforce (across the whole pathway) has the knowledge, skills, competence and capacity to meet the specific needs of children and young people with acute, long term, complex, palliative care, mental health and emotional well-being needs, as well as to promote health and address public health issues across a given population.

We support Sir Bruce Keogh's ambition[28] that nurse staffing levels and skill mix will appropriately reflect the caseload and the severity of illness of the patients they are caring for and be transparently reported by Trust Boards. We wish to ensure that children and young people's care is explicitly included in this ambition.

Failure to ensure an appropriately skilled and competent children and young people workforce has in the past led to significant shortfall in numbers of trained staff. For example, the Centre for Workforce Intelligence report about children's nursing[29] resulted in decreased commissions for undergraduate programmes. However, a report of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD)[30] clearly identified a significant shortfall in the availability of registered children's nurses to fill posts in areas such as emergency care departments, children's surgical wards and day case surgical units providing services for children and young people.

Furthermore, we are aware children are currently not receiving recommended levels of consultant-delivered health care for much of the time. The RCPCH published and has audited ten standards for acute paediatric care in *Facing the Future: A Review of Paediatric Services* in 2011[31,32]. However, only 25.6% of units across the UK report a consultant being present at times of peak activity on weekdays, and only 20.0% at times of peak activity at the weekends.

Throughout the Forum's work, we have been concerned that there are clear plans to ensure a sustainable and diverse children's workforce, recognising that there is increasing pressure to concentrate valuable and skilled resources into fewer sites in order to maintain and improve patient quality and outcomes. This is what underpinned our original recommendation[33] that, *as a matter of priority, the Centre for Workforce Intelligence, in conjunction with key professional bodies undertake a scoping project to identify and address the issues of providing a safe and sustainable children and young people's healthcare workforce*. We are pleased that this has commenced but disappointed by the slow pace. In addition, whilst acknowledging the ambition and progress in achieving a significant increase in the number of health visitors, we are particularly concerned at the lack of progress in response to our recommendations for improvements in general practice and the primary care workforce for children.

5. Patient safety – specific issues that are most relevant to children and young people

Robert Francis stresses the need in any system to ensure a relentless focus on patient safety. Safety absolutely depends on culture – and for children and young people this means a culture focused on their specific needs. In its first report, the Forum closely allied issues of safety with service sustainability, focusing on the need to have an appropriately trained workforce and a sustainable configuration of services. In addition, we identified some of the components of safe and quality driven services for children and young people. Services must be designed with a full understanding of their needs and with their

involvement. Without this, unsafe care will result, and lead to poor outcomes including, at worst, avoidable mortality.

The Forum's first report identified that too many health outcomes for children and young people are poor, and for many this is involved with failures in care. This includes all-cause mortality for children aged 0–14 years, which has moved from the average to amongst the worst in Europe. Previous confidential enquiries[34] have identified that over 25% of children's deaths occurring in hospital have avoidable factors. We also recognise that current methods of assessing mortality rates, such as the Hospital Standardised Mortality Ratio, are designed for adult hospitals and do not seem to be appropriate for children. Reducing avoidable mortality is a key aim for quality improvement and, despite the relatively small numbers, is a crucial improvement area for children's healthcare.

The Forum recommends that all hospitals treating new-born babies, children and young people follow a defined methodology, whereby every death is independently reviewed by a children's 'Hospital Mortality Review Group' which includes a patient representative. Trust Boards should scrutinise non-identifiable summaries of every infant and child death, and details of lessons learned should be published in the Board minutes and Quality Accounts. Boards must assure families, regulators and commissioners that any recommendations are implemented within the timescale set. Good practice demands that families receive direct and timely oral and written feedback from the clinical team.

The Forum would also like to see NHS England support the development of a standardised mortality assessment that is relevant for assessing children's services.

The Forum's first report has already prompted significant action to improve safety for children and young people in health services. NHS England has committed to leading the development, through the patient safety domain, of a children and young people's patient safety strategy, including an implementation plan based on the NHS Outcomes Framework. We welcome NHS England's decision to establish a Children and Young People's Patient Safety Expert Advisory Group, with its remit to drive the patient safety agenda for this vulnerable group.

In this context, it is important to recognise that the profile and impact of major patient safety issues for children differs somewhat from that for adults. The major safety incidents that affect the care of children and young people concern

- medication errors
- unexpected or unrecognised clinical deterioration
- loss of skin integrity
- hospital acquired infection, in particular respiratory viruses, gastroenteritis, surgical site infections and central line infections.

One of the aspects of the patient safety work on clinical deterioration in children is highlighted in the NHS England Compassion in Nursing Strategy. Work is underway by a collaborative of several children's services to bring together a monitoring and improvement proposal called the Paediatric Safety Scan – to mirror the adult 'NHS Safety Thermometer'[35]. This includes the use of a 'Paediatric Early Warning Score' in which a child's clinical observations are recorded and which, along with clinical opinion, gives an early indication that further intervention or escalation of care may be required.

The only way that children, young people, their families and the public have of knowing how safe the services they use are, is through the publication of clear and transparent data on outcomes. There is an interesting debate and some difference of opinion discussed in

Professor Berwick's report about the feasibility of achieving or aiming for 'zero harm'. Nevertheless, it is our view that it is unacceptable that any child or young person suffers a medication error, acquires a serious infection in hospital, loses skin integrity, or suffers an unrecognised deterioration that results in harm.

Whilst these safety issues are predominantly the concern of children's wards, one area of considerable disquiet is the placing of young people on adult wards. Evidence shows that young people achieve better health outcomes when on adolescent wards or, if adolescent beds are not available, then on paediatric wards. They have the worst health outcomes when placed on adult wards[36]. We have particular concern about the safety and outcomes of young people with mental health problems placed on adult mental health wards – which, of course, contravenes the Mental Health Act 2008.

We recommend that the key safety indicators for children and young people, which include the four outcomes above, together with the number of young people on adult mental health wards, should form part of services' patient safety reporting to commissioners.

In its first report, the Forum recommended a number of changes to indicators in Domain 5 of the NHS Outcomes Framework, "Treating and caring for people in a safe environment and protecting them from avoidable harm", including *a new indicator on rates of admission to age inappropriate environments for children and young people*. We proposed a similar new indicator, specifically with regard to children and young people with mental health problems, for Domain 4 ("Ensuring that people have a positive experience of care") of the Commissioning Outcomes Framework, as well as several new indicators for its Domain 5[37]. **We recommend that the Department of Health investigates the feasibility of introducing each of these new measures as a matter of priority**.

We further recommend that NHS England should develop a roll-out of programmes using improvement methodology through the Strategic Clinical Networks (including that for Maternity and Children's Services) to address each of the specific safety elements relevant to children and young people.

Safeguarding children and young people remains an afterthought in too many settings and, whilst we continue to read about highly public tragedies, the Forum is immensely concerned that too many children continue to be subject to physical, sexual or emotional abuse or neglect and that the scale of this is seriously underestimated by organisations within the system.

In its first report, the Forum made a number of recommendations[38] about safeguarding. In particular, it was concerned about the lack of a clear accountability framework for safeguarding children. We therefore welcome the publication of such a framework by NHS England in March 2013[39], alongside the Department for Education's revised statutory guidance[40]. We are also pleased that a number of our other recommendations are being taken forward, including the commissioning of further guidance from NICE prior to the development of a quality standard for safeguarding children.

Safeguarding is a vital element of the safety agenda for children. We want to see action on all of the Forum's original proposals.

6. Summary

In his report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, Robert Francis highlights the importance of culture, leadership, workforce capability and safe and effective

care. In this report, we have considered the particular implications of each of those factors for children and young people, informed also by the subsequent reports by Professor Don Berwick and Sir Bruce Keogh. We propose a number of ways in which to build on our first report from 2012 and the shared ambitions articulated in the February 2013 Pledge.

Although Francis focuses primarily on NHS hospitals, the core messages are applicable to all staff and organisations working across the health and care system, whatever the setting. Corporate failings are not restricted to a single sector of care providers. The interests of patients and service users need to be foremost, whatever their individual needs and wherever they are cared for. We need a universal children and young people friendly culture.

The acceptance and implementation of the proposals the Forum has made in this response have implications for service commissioners, planners and providers, and for those responsible for quality control, safety, regulation and improvement. We expect our recommendations to inform the further response to Robert Francis's report (to be published this autumn), including the review of the complaints process for acute health care, as well as the NHS Constitution refresh and the review of the UK Government's implementation of the UN Convention on the Rights of the Child.

The Forum will continue to work with Department of Health colleagues and wider partners, and with children and young people, to build on this response to the Mid Staffordshire Public Inquiry Report, and to improve health outcomes for children and young people.

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[18] Op. cit., p.49

[19] Op. cit., p.24

[20] Op. cit., p.3

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