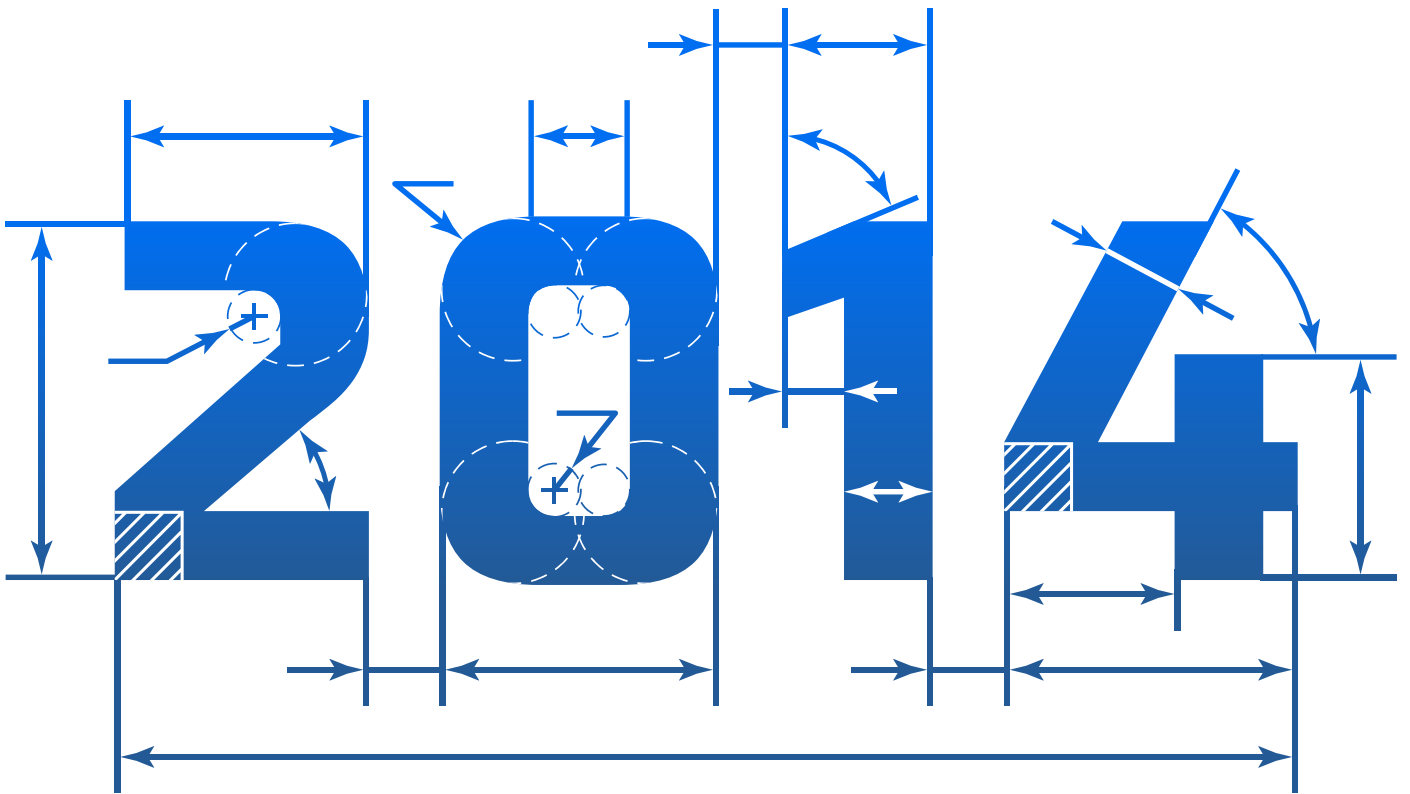


THE NATIONAL COUNCIL FOR PALLIATIVE CARE



Impact Report 2014

Chairman's Foreword – Professor Mayur Lakhani

I am absolutely delighted to be reporting back on such a busy and successful year for the National Council for Palliative Care and for the Dying Matters coalition which we lead.

Against a context of lots of change, both inside the organisation and externally within health and social care, we have kept our focus and unwavering commitment to making a difference. Whether it's been through informing and influencing policymakers and politicians, supporting health and care professionals, enabling people with personal experience to have their voice heard or our groundbreaking work leading the Dying Matters Coalition, we have been at the centre of ensuring people who are dying and their families get a better deal.

The undoubted impact we have would not have been possible without the fantastic support we have received from NCPC's subscribers, Dying Matters members, our funders and our partners, for which we are very grateful. We look forward to continuing with our work to change the nation's approach to dying, and will do all we can to ensure we have even greater impact in 2015.



Chief Executive's Foreword – Claire Henry

Since taking over from Eve Richardson as the organisation's Chief Executive in April 2014, it's become clearer than ever that because of the way in which the National Council for Palliative Care works in partnership we truly punch above our weight.

As you can see from this short report, which highlights a tremendous range of achievements and impact during 2014, we have been active in leading and supporting a real variety of work which is making a difference to how dying people and their families are cared for and supported.

With a new three year strategy for NCPC and innovative and exciting plans for the future, this is a key period for the organisation as well as for end of life care. We're also delighted that we have just won a prestigious GSK IMPACT Award for our work. With your support, we know we can achieve even more in the future.



Changing attitudes and behaviour

The National Council for Palliative Care continues to be at the forefront of changing the nation's approach to dying. Through our work leading the Dying Matters coalition, people are becoming more comfortable talking about dying, death and bereavement and more likely to make their end of life wishes known.

- Our report, 'Life after death: six steps to improve bereavement support', published with the National Bereavement Alliance, was covered throughout the media, with particular interest including from employers in **our calls for a review of bereavement support in the workplace**. Following the report we were asked by ACAS to join an advisory group to oversee the development and launch of new guidance for employers on compassionate employment.
- In support of our awareness-raising activities we developed new partnerships, **including with NHS Blood and Transplant** with whom we signed a three-year partnership agreement. As part of this we jointly published a new leaflet on the importance of sharing your organ donation wishes and worked together on awareness-raising activities.
- We have seen a **growing interest from the media in our work** and were extensively contacted by print and broadcast media. We worked with several production companies, including Love Productions as part of their 'My Last Summer' series which aired on Channel 4. Channel 4 have since fed back that 84% of viewers questioned in independent research said that it made them think about the challenges facing those with a terminal illness, and their families, in a different way, 77% said that the series highlighted the hard work of staff in treating terminal illness, two-thirds of viewers said that it improved their opinion of end of life care and over half of viewers questioned are now more likely to discuss the subject of death with their friends and family.
- The new, improved version of our '**My Funeral Wishes**' leaflet produced with the National Association of Funeral Directors has been very well received, with thousands of downloads and over 15,000 copies of the leaflet requested. We also secured considerable discussion and debate when we launched the revised leaflet, including on BBC Breakfast TV and BBC Radio 5, and in The Sunday Times, People, Times, Metro and Daily Mail, plus extensive regional media coverage.
- Dying Matters has had continued success in **growing a broad and engaged membership**. We have over 30,000 members from across the voluntary, public and private sectors, gaining over 1,250 new members during 2014.
- The **Dying Matters website has gone from strength to strength**. In 2014 there were 977,792 page views (compared with 717,109 in 2013 – an increase of 36%) and 352,712 unique visitors (compared with 204,455 in 2013 – an increase of 73%). The number of followers for the Dying Matters coalition on twitter increased from just under 13,000 at the start of the year to over 22,000 by the end of 2014. Facebook likes increased from 2,650 in January to 4,150 by December.
- We formally launched **Byw Nawr (Live Now) - Dying Matters in Wales**, with the support of the Welsh Government. Two very well attended conferences were held during Dying Matters Awareness Week and our awareness week materials were available in Welsh for the first time ever.

- There continues to be a **significant amount of international interest in our work**. Highlights included National Palliative Care Week in Australia choosing to build on the impact of Dying Matters Awareness Week, using the same theme and many of our messages. The US-based Huffington Post ran a major spread about Dying Matters Awareness Week, praising the work of Dying Matters and comparing it favourably to “disjointed” work in the US. Dying Matters also worked closely with the (South) Korea Educational Broadcast System as part of a major three-part TV series, looking at attitudes to dying including the work of the Dying Matters coalition.

“Fabulous, open conversations were had with people of all age ranges and a great ripple effect was created as passers-by encouraged other colleagues to come and talk with us about their plans. People openly shared their personal stories and used these to influence more concerned others to spend a little time considering their wishes and how best to ensure that they are met when the time comes. A most positive and life affirming event with a hint of denial but also much laughter.”

NHS Improving Quality

- We successfully launched our new ‘Being there’ campaign, aimed at **supporting people with what to say and do when someone has been bereaved**. Media coverage for the campaign and a new Dying Matters leaflet with suggestions of how to support people who have been bereaved included BBC Radio 5 Live, BBC News Online, BBC World Service and throughout BBC regional and independent local radio. As a result of the campaign’s launch we have joined forces with a Dying Matters member, Inspired Goodbyes, to produce a new range of ‘Being there’ bereavement cards. These are intended to be more sensitive and personalised than most existing cards. NCPC receives a proportion of the proceeds from each card sold.
- In addition to our Dying Matters Annual Lecture, we held two **major events to showcase Dying Matters member activities and galvanise engagement** – a national event to gear members up for Dying Matters Awareness Week and our Day of the Dead event in November. Both events were very well attended and received very positive feedback.
- Dying Matters has provided expert support to several web-based projects and applications, aimed at **supporting people to plan ahead**, for example through advance care planning – and been actively involved in signposting to these.

Future priorities include:

- Working with partners to ensure greater public awareness about the importance of care planning
- Building on the momentum of our ‘Being there’ bereavement campaign to raise awareness about the importance of talking more openly about bereavement. Plans include developing a campaign for Autumn/Winter around remembrance
- Identifying funding to develop a programme of work to support engagement with children and young people around talking about dying, death and bereavement including in schools
- Continuing to grow the Dying Matters coalition, including through media and social media campaigns, signing up new members and recruiting high profile supporters
- Seeking support to take forward a Dying Matters campaign on the importance of making financial plans

In focus: Dying Matters Awareness Week 2014

Dying Matters Awareness Week 2014 was our most successful yet, with record levels of member events, media coverage, website traffic and social media interest.

- Over 530 events were held across England and Wales. At a very conservative estimate based on a post-awareness week survey member activities reached an estimated 573,100 people. Total estimated investment reported from Dying Matters members was £118,250 and 8,835 volunteer hours were contributed.

- We secured over 650 separate pieces of media coverage, including in *The Times* (including a supportive editorial), *Daily Telegraph*, *Sunday Express* magazine, *Guardian*, *Daily Mail Metro* and across health and medical media. There was also substantial broadcast coverage, including interviews for *BBC Breakfast TV*, *BBC Radio 5 Live* and *Sky News Radio*, as well as discussions across the *BBC*, independent radio and on *ITV's This Morning* programme.

- There were 53,351 page impressions for the Dying Matters website during Dying Matters Awareness Week, an increase of 5% on 2013. Unique visitors were up by 22%. The hashtag #YODO (which we promoted in relation to the theme of the awareness week: You only die once) was used 8,789 times on twitter during the week. Many members shared links to visuals of our YODO posters and leaflet which details five steps people can take to plan ahead – a very effective way of highlighting our key messages.

“Congratulations on Dying Matters Awareness Week, the content has been really interesting and your media coverage has been amazing”

Clare Maskell Gibson of Palliative Care Australia



- Events and activities included a pop up shop in Camden organised by *DeadSocial*, art exhibitions including 'A Graceful Death' by artist *Antonia Rolls*, an event in Leicester drawing on the burial of King Richard III and the archaeology of the dead and 'Before I die' boards in the centre of Hereford which subsequently featured in the Hay Festival. Significant numbers of MPs and local councillors visited events organised by Dying Matters members, as did HRH Princess Michael of Kent, who wrote her own personal Bucket List wish to add to the board on display at Peace Hospice Care.

- We also took Dying Matters to high streets up and down the country. Many of our members who have charity shops, including all Sue Ryder shops, displayed Dying Matters materials. We also worked with Skipton Building Society to make Dying Matters materials and planning tools available in all of their branches. This was accompanied by a marketing campaign by Skipton to its customers.

- The second annual Dying Matters lecture was held in May 2014, supported by the Royal College of Physicians, and featuring hospital doctor Kate Granger who is terminally ill. The well attended event, which was chaired by Alison Holt, the BBC's Social Affairs Correspondent, featured a panel discussion with Kate Granger, her husband Chris and three doctors who reflected on what they had learnt from Kate's approach to dying. The event also saw the premier of a new Dying Matters film, 'Kate's story', which was viewed online 10,000 times in the first month alone.

- We directly distributed over 350,000 Dying Matters resources and promotional items in the lead up to the awareness week.

“I’ve had phenomenal support since penning this intensely personal story and last week appeared on the BBC News Channel, BBC One O’Clock News, ITV lunchtime and evening, and Sky News. I also spoke to BBC Radio Five Live and my audio was shared with various regional BBC radio stations. The Independent wrote an in-depth article and leader column about care for the dying and I’ve done a very sensitive interview this week with the Wolverhampton Express & Star. I had to turn down approaches from other national news programmes as I just couldn’t be in two places at once. This was because my blog post was picked up by Dying Matters during their ‘you only die once’ awareness week. This was my opportunity to be heard, and thanks to Dying Matters. As you can imagine, for someone who wrote a blog post wanting just to be listened to, I never suspected I’d end up speaking to millions through national media. It was a cathartic experience for which I’m immensely grateful”

Linda Aitchison

We have been working in partnership to improve care and support

We want to ensure that the quality of care and support that everyone experiences in dying, death and bereavement is of a high standard. That's why we work with adult services in England, Wales and Northern Ireland, and with our partners in children and young people's services across the UK and Ireland to ensure that end of life and palliative care remains a priority for policymakers, politicians, commissioners and service providers.

- All of our work has been shaped **by people's own experiences of end of life care** and support after bereavement. Our People in Partnership Group has steered and shaped our work, and along with our People Bank they have also been involved in working with our partners and speaking on end of life issues.
- We published our new **Difficult Conversations for Heart Failure** guide, with the British Heart Foundation, which has been widely distributed, and also worked with Together for Short Lives on a new of 'Difficult Conversations for Young Adults' publication.
- We published two short guides to **improve the way that carers are supported** and involved when the person they're caring for goes into hospital. These have been shared widely and we have received excellent feedback on them.
- We completed a project in partnership with the Social Care Institute for Excellence (SCIE) to explore what people think and feel when they hear the terms 'palliative' and 'end of life care'. We heard from over 1,500 people by email, online survey, through events and other approaches. The short film we produced with SCIE is now being used to **help improve communication when people are dying or bereaved**.
- We **worked with the Care Quality Commission (CQC)**, providing case studies of what 'good' end of life care looks like, especially for vulnerable people who don't easily access care, to inform CQC inspections.
- Following on from our 2012 report into whether **Health and Wellbeing Boards** had included plans to improve end of life care in their strategies, along with Hospice UK we published an updated survey. This found that since our initial report, which led to several Boards getting in touch for our support, a growing number had given consideration to the needs of dying people - although this needed to be repeated throughout the country.
- Our response to the National Care of the Dying Audit for Hospitals report, published by the Royal College of Physicians, was **extensively picked up by the media**. We were quoted on the front page of the Daily Telegraph, as well as in the Daily Mail, Mirror and Independent; we were also interviewed by broadcast media including Sky News. We supported people with personal experience to share their stories about end of life care throughout national media in response to the report.

- We continued to play an important role in informing and influencing politicians – including providing the secretariat to the **All Party Parliamentary Group on Hospice and Palliative Care**, which held meetings on issues including social care at the end of life, and care of the dying after the Liverpool Care Pathway.
- We **attended and held fringe meetings at the three main party conferences** on the issue of health and social care integration, and produced a **joint manifesto briefing** with end of life care partners to help MPs and prospective parliamentary candidates understand our election calls.
- **Keeping our subscribers and partners up to date** with all of the latest developments in end of life care and with our activities has been a key part of our work. As part of an improved subscriber offer we introduced a new weekly subscriber bulletin as well as a new series of briefings on key issues including the Better Care Fund and the NHS 5 Year Forward View.

“As someone relatively new to the area of end of life care, I found the event gave an excellent overview of many important issues in this area.”

Attendee, NCPC conference

- Our events programme was **well-attended and well received**, with all of our events rated by the majority of delegates as “very good” or “good”. A wide range of health and care professionals attended conferences which showcased good practice on improving end of life care in acute hospitals, end of life care for people with heart failure, coordinating social care and health care, the ethics of choice and ambitions for end of life care.
- We **worked with Clinical Commissioning Groups (CCGs)** to support their work on end of life care. This included facilitating and presenting at End of Life Stakeholder Engagement Events for Barking and Dagenham CCG, and subsequently producing a report for the local authority and CCG with recommendations on how to improve their end of life offer.



- Working in partnership with Public Health England we launched the **Dying Well Community Charter** and selected eight pathfinders and six buddies to implement it.
- We responded to a wide range of consultations including on the **Care Act and the Commission on the Future of Health and Social Care in England**. We were delighted that end of life care featured prominently in the Commission's final report, including our calls for free social care at the end of life.
- NCPC's Chief Executive Claire Henry was asked by Norman Lamb MP, Minister for Care and Support, to **lead a review into choice at the end of life**. As part of this work we led on engaging with people with personal experience to ensure their views informed the review's recommendations.
- We provided training to **GPs and other health and care professionals**, including as part of the Dementia Challenge. This has been really well received, with excellent feedback.
- Find Me Help, the most **comprehensive database of services for people nearing the end of their lives** and those close to them, has continued to improve. We now have details of 1,168 organisations providing 3,295 services. Find Me Help also contains a clear and helpful guide for those approaching the end of life and their carers, relatives and friends. We also launched version which can sit as part of a partner organisation's website.

Future priorities include:

- Policy influencing work on key areas in end of life care including ensuring the findings and recommendations of the Choice Review are taken forward. We will also be supporting the publication of a new 5 year vision for end of life care, as part of our work with the Ambitions Partnership.
- Political and parliamentary engagement, both pre-election to shape party manifesto commitments and post-election to ensure end of life care remains high on the agenda of government and of newly elected MPs
- Development of a new Involvement Strategy to ensure we are effectively involving and engaging people with personal experience throughout our work
- Supporting the Dying Well Community Charter Pathfinder programme, and ensuring learning from the pathfinder areas is shared
- Providing practical support to those working in end of life care. As part of this we will be seeking support to produce new guidance, including a Difficult Conversations in Care Homes publication.

Improving evidence and intelligence is an increasing priority

We believe that improving the evidence and intelligence that is available about the challenges facing end of life care and the extent to which people's needs are being met by current and planned provision is absolutely essential. That's why this is a real priority for NCPC: we believe we have a key role to play in helping to improve the evidence and intelligence base through how we collect this ourselves and through ensuring this is a priority for all those involved in end of life care.

- We published a new edition of the **Specialist Palliative Care Workforce Survey**, commissioned by Public Health England. As a result of the survey's findings we raised concerns, which were covered by health media, that the care of people who are dying could be put at risk due to a growing recruitment crisis and ageing workforce. We also raised concerns about the quality of some of the data collected, and are going to be working with an academic partner to further understand the reasons behind this.



- The latest **Minimum Dataset for Specialist Palliative Care Services (MDS)** report, giving valuable insight into specialist palliative care provision across England, Wales and Northern Ireland, was published. We changed the format of the reports we provide to MDS contributors, not only giving them comparisons with other services of similar size or in their region, but also letting them look at their responses across the past six years so they can use that data to assess changes in their service provision or improve data quality.
- We worked in **partnership with Public Health England and Hospice UK** on the scoping and piloting of an individual-level dataset for palliative care.
- Working in partnership with Hospice UK and NHS Improving Quality we **surveyed the palliative care sector** on IT provision. The results of this will help to support the proposed individual-level dataset, the continuing rollout of Electronic Palliative Care Co-ordination Systems (EPaCCS), the introduction of a palliative care funding currency and the continued collection of the MDS.
- We continued to make the case for greater investment in improving the evidence base for end of life care. As part of our joint manifesto statement **we called for an increase to the proportion of the medical research budget** dedicated to developing better ways of caring for terminally ill people and their families. Just 0.1 per cent of the total medical research budget (10p in every £100) goes to research concerned with end of life care and terminal illness.
- **Measuring our own impact** has been a priority for us, and will continue to be so. We gained really helpful – and very positive - feedback on our work through a survey of NCPD subscribers, and also made improvements to how we track the response to work, including our electronic communications.

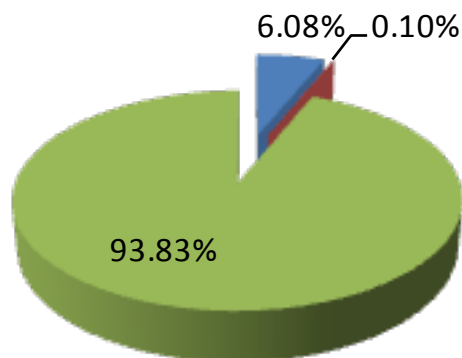
Future priorities include:

- Producing updated MDS reporting for 2015/16 to better capture aspects of holistic care and giving individual services even more information about their own data to help with service development and improvement
- Supporting Public Health England with the piloting of their new dataset which will capture information about palliative care activity at patient level
- Drawing together existing sources of information on the palliative care workforce to inform a report on actions that need to be taken to ensure good quality care can be delivered
- Working with Hospice UK to help the specialist palliative care sector make better use of data

Financial statement

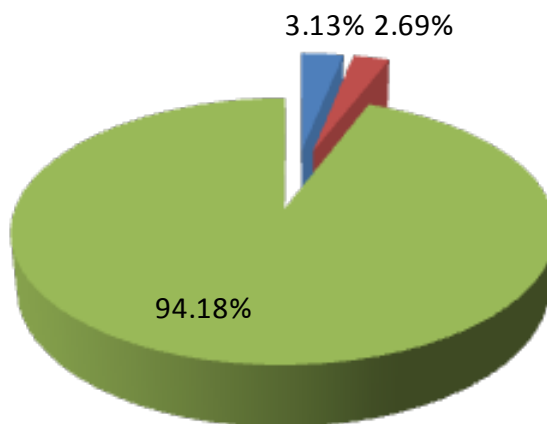
Income 2013-14

- Voluntary income
- Investment income
- Incoming resources from charitable activities



Expenditure 2013-14

- Cost of generating funds
- Governance
- Charitable activities



Money spent on charitable activities includes:

Public awareness	£350,402
Policy and development	£486,075
Information, publications and events	£232,802
Training	£314,679

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

Since 2009 NCPC has led the Dying Matters coalition. Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430.

NCPC is governed by a Board of Trustees appointed for their expertise in health and social care:

Professor Mayur Lakhani FRCGP CBE - Chairman

Rev Keith Albans

Dr James Beattie

Tony Bonser

Dr Jane Bywater

Ruth Dixon

Mike Hobday

Richard Huxtable

Jaki Meekings

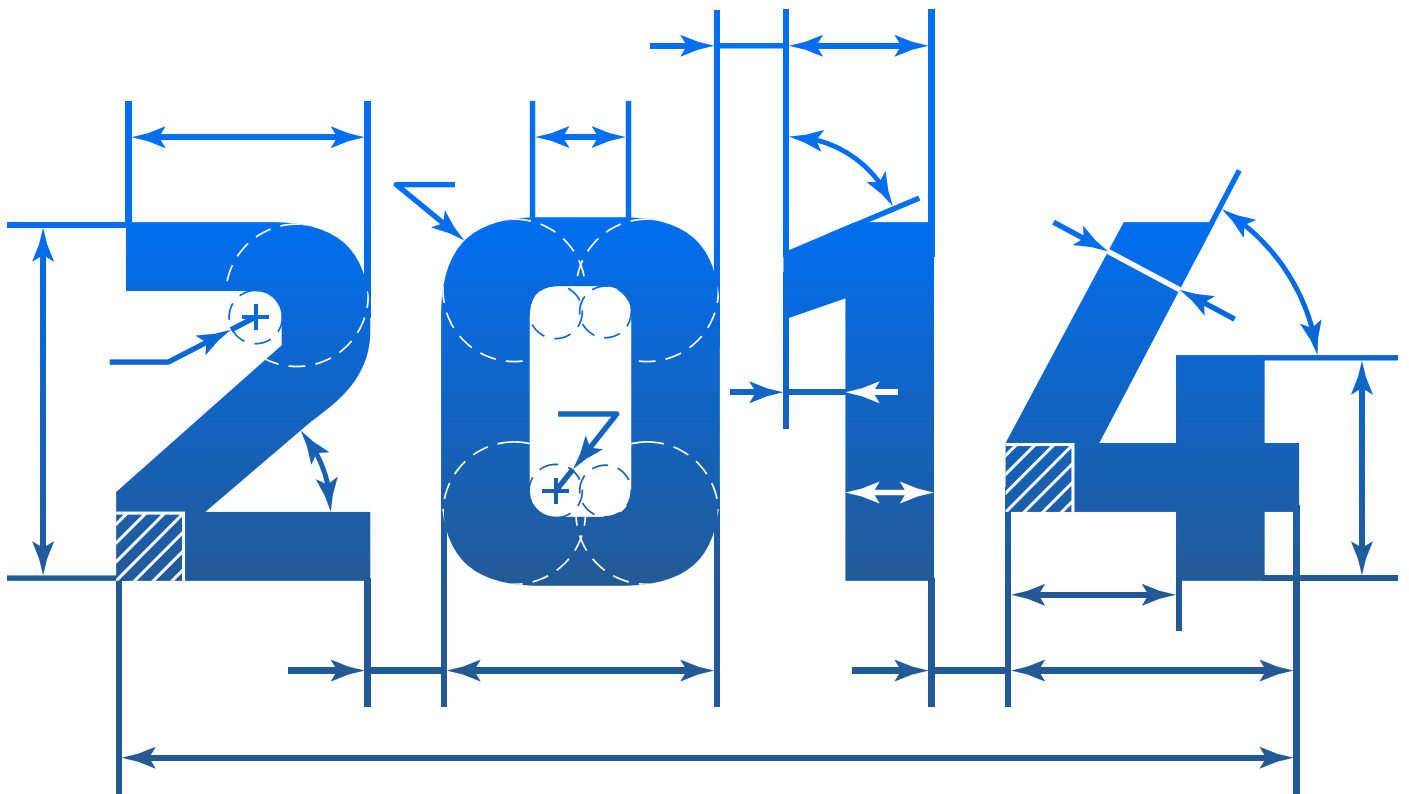
Sarah-Jane Mills

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