The voice of people affected by RA in the UK
Since the turn of the century, we have seen the treatment of Rheumatoid Arthritis change in a revolutionary way. In fact every year since the launch of NRAS in 2001, we have seen major growth in the research of the pathogenesis of RA, spawned by the advent of Anti-TNF. Innovative new treatments continue to be introduced to meet the unmet need of those whose disease is, or becomes, unresponsive to currently available therapies. There has justifiably been much emphasis on early diagnosis, treat to target and tight control strategies all of which have been championed by NRAS. NRAS has also been strategically involved in the development and introduction of national guidelines and standards which promote best evidence based treatment and care for all.

In spite of this remarkable progress, there remains significant unmet need and wide variation in the standards of care which people can expect to receive, and our job of supporting people living with this painful and progressive disease remains as important today as it was over 12 years ago when we launched.

Ailsa Bosworth
CEO
NRAS has also been strategically involved in the development and introduction of national guidelines and standards which promote best evidence based treatment and care for all.
About us

The National Rheumatoid Arthritis Society is ‘the voice’ of people affected by Rheumatoid Arthritis (RA) across the whole of the UK and in due course, we hope to be so for Juvenile Idiopathic Arthritis (JIA). Founded in 2001, we are the only UK charity devoted specifically to RA, and we are launching a service for families, children, young people and adults affected by Juvenile Idiopathic Arthritis in July 2014.

We take pride in the fact that everything we stand for and do is patient-led. Our head office team of 24 members of staff works closely with all of our NRAS Members and Volunteers, the Board of Trustees and our panel of Medical and Allied Health Professional Advisors to design, coordinate, fund and deliver a comprehensive and wide range of high quality products and member services for all affected by RA and, in due course, JIA.

Our Core Values

We approach our commitment and responsibilities to all with empathy, professionalism, passion and enthusiasm. We continually strive to achieve the best results and outcomes that we can for those we represent. These core values underpin the way we work.
At all times, we act:

TRANSPARENTLY  We work openly and ethically, with integrity, honesty and independence

INNOVATIVELY  We are creative and constantly challenge the status quo, always striving for better and looking for new ways to add value, whilst basing what we say and do on the best evidence and our Members’ experiences

PASSIONATELY  Our staff are not just enthusiastic and committed, they are passionate about making a positive difference for all those we represent

COLLABORATIVELY  We work with many different organisations, contributing significantly to alliances and coalitions

DYNAMICALLY  We are results focused and deliver on our projects and campaigns. Our many awards are testament to our achievements

INCLUSIVELY  We act with sensitivity and compassion, respecting the needs and preferences of the individual regardless of creed, gender, age or ethnicity, while at the same time representing the entire community affected by RA or JIA in the UK, encompassing adults and young people, families, carers and rheumatology healthcare professionals

“NRAS has been a tower of strength for me in recent difficulties in management of my RA. They respond to queries swiftly and helpfully.”

Helpline Caller
At the start of 2014, NRAS has embarked on a further period of expansion both in terms of staff and new services. It is therefore an exciting period in the charity’s development but also a challenging one as we ensure that our core services which our Members, the wider public and our partners have come to rely on, continue to be first class and to evolve and grow as we move in new directions.

We have settled into our new home at 4 The Switchback in Maidenhead, where we have room to accommodate our growth over the coming years, secure in the knowledge that we are providing a pleasant and stimulating environment for our team to do what they do best, serving the interests of people affected by Rheumatoid Arthritis and the health professionals working within the rheumatology community across the UK.

We shall be investing in our fundraising capability and pursuing new income opportunities for our new service for families and young people affected by JIA. We also anticipate that within the next 12 months, the new arm of the charity, NRAS Community Services Ltd, being established to deal with our directly commissioned patient and consultancy services, including the RA Self Management Programme, will start to contribute income to support NRAS’ principal activities for the benefit of everyone living with RA.
**Our Mission**

- Ensure that people affected by RA have the information, tools and support to be able to access high quality care and services best suited to their individual needs and preferences.
- Do everything we can to raise standards of care and ensure equitable access to high quality care and treatment for all with RA.
- Pioneer innovative and effective ways to support all those living with RA to lead full and active lives with maximum well being, able to pursue their individual goals.

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**Our Vision**

Everyone affected by RA to be able to live the life they want to

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“I have been a member of NRAS since the very early days after reading an article about Ailsa in a newspaper. I became a volunteer probably almost 6 years ago after attending the Healthcare Champions Awards at the House of Commons. Whilst there I got chatting to Clare Jacklin and Paul Keats about patient groups. Their enthusiasm inspired me to become a part of it. After lots of emails, phone calls and a two day training course I became a volunteer coordinator. With the support and guidance from head office our NRAS group was launched. Also, I regularly make support calls to other RA patients. Throughout my NRAS journey I have always felt that they have supported me whilst not only the group has grown but I have also grown in confidence.

Being involved in NRAS has taken my life on a pathway that I would never have imagined. I have been interviewed for a magazine, on the radio, for newspapers and a booklet. Plus attended conferences including one in Iceland!!

The NRAS staff are all very friendly and appear to love their job. Whilst I can see that they work incredibly hard they always remain professional and you do not hear them complaining.

I have known some of the staff for a few years now so view them as friends, it is always lovely to see them. I do feel that they value the work of the volunteers and understand the condition so realise that sometimes we have to say No, when we are unable to help.

I do feel that NRAS are thriving and are always aiming to improve the lives of people living with RA. I feel proud to be a part of the organisation.

NRAS VOLUNTEER
Our comprehensive range of services includes the following:

- Free professional helpline
- Comprehensive website
- Range of Information Standard accredited publications and other sources of information
- Membership, with full range of benefits
- Health professional membership programme
- National volunteer network
- Community based NRAS groups across the UK
- Peer support service
- Self management education – RA Self Management Programme
- Education and training (for people affected by RA and for the Health Professionals working in rheumatology)
- Ambassador programme for the devolved nations
- Campaigns, government and public affairs programme
- Media and communications programme to raise public awareness of RA and the needs of people affected by RA
- Fundraising events (national and local) to fund and support our work
- Range of directly commissionable services and consultancy through NRAS Community Services Ltd and through the Musculoskeletal Support Alliance (collaboration with BSR and Arthritis Care)
- New Service for children with Juvenile Idiopathic Arthritis launching July 2014 – ‘JIA-at-NRAS’
Our Principal Activities include:

- Supporting, informing, educating, and advocating on behalf of people with RA, their carers and families and health professionals in rheumatology
- Improving patient self-management skills and helping people to learn to successfully navigate the NHS system and participate fully in shared decision making
- Raising public awareness of RA
- Contributing to the creation and development of national guidelines and standards of care
- Providing information and expertise to external organisations such as NICE and NHS England
- Providing a range of supported patient self-management programmes and services which can be directly commissioned
- Providing consultancy services to Clinical Commissioning Groups and Clinical Support Units as part of the Musculoskeletal Support Alliance
- Campaigning at national, regional and local government level to improve access to services
- Influencing stakeholders, commissioners and key opinion leaders on RA related issues
- Working collaboratively with the musculoskeletal community and relevant disability organisations
- Working in partnership with health professional organisations and other charities within the field of musculoskeletal disease
- Conducting our own social research in respect of the impact of living with RA
- Supporting clinical, academic and social research in the UK
- Contributing patient research partners to national and international research programmes
- Contributing to the development of patient reported outcome and experience measures
- Developing a service for children, families and young people affected by JIA
Strategic Aim 1

We will continue to be the “go-to” organisation for people with RA

Our aim is to provide everyone living with RA a high quality, fully comprehensive range of services to enable them to take control of their disease and achieve a better quality of life and state of well being. We provide a wide range of free high quality, reliable, evidence-based information services, such as booklets, publications and online resources. All of our information is Information Standard accredited.

1. We will work hard to ensure that the diverse population we represent can access our information and support, including peer to peer support, in an increasingly wide range of formats to suit individual choice.
2. We will collaborate closely with other patient, professional and advocacy organisations, so that we can signpost our members to an even greater range of resources and support.
3. We will consistently seek feedback from our members and those who use our services to improve the quality and relevance of the services we provide.
4. As technology evolves we will innovate to re-shape existing services and introduce new ones, adapting to the needs expressed by our membership and the wider RA population.

By 2017
We aim to reach many thousands more who need our help through the innovative evolution of our front line services and social media and we will also start to make inroads into hard to reach communities. 2014 will see the start of a targeted campaign to better understand the needs of the South Asian communities in the UK and by 2017 we will have developed some specific services for this community.
Strategic Aim 2

We will work to change care and services for the better

We are passionate about ensuring that everyone affected by RA has access to the best quality services and care irrespective of where they live. This means campaigning for greater public awareness, earlier diagnosis, more coordinated and integrated care, and timely access to the best rheumatology health professionals, medicines and treatments appropriate to the physical, mental and social needs of the individual, their family and carers.

1. We will work collaboratively with a wide range of rheumatology and community professionals involved in the delivery of healthcare and social care, to better educate them about the needs of patients and families affected by RA.

2. We will continue to work with government departments, the NHS and external organisations such as NICE, the British Society for Rheumatology and the British Society for Paediatric and Adolescent Rheumatology to provide strategic patient input to Health Technology Appraisals, Guidelines and Standards and national audit related to RA (and JIA).

3. We will continue to provide input to Patient Outcome Measures and Patient Experience Measures as the NHS moves further towards outcome based commissioning.

4. We will facilitate meaningful patient involvement in shaping future care models through a variety of mechanisms including outcomes development, clinical research, service redesign and training of healthcare professionals.

5. We will also support shared decision making. However, this must be relevant to patients, giving a range of sufficient information and support to enable patients to make key decisions about their own care.

By 2017

We aim to take action to improve the mechanisms by which good practice can be cascaded and shared more widely than currently is the case. We will also work proactively with rheumatology teams in the devolved nations to raise greater awareness of the support NRAS can provide at a local level both for the benefit of their patients with RA and for their service.
Strategic Aim 3

We will empower, educate and encourage people affected by RA to lead full lives

People affected by RA have a range of needs, not just clinical or medical ones. Our job is to give people the tools, confidence and support to help them to manage their disease well, enabling them to confidently take active control of their lives and live life to the full. We do this through our front line services such as helpline and peer to peer support, our specially developed RA Self Management Programme, our print and online information services and via our network of volunteer-led local NRAS groups.

1. We will increase our NRAS groups each year from 2014-2017 enabling more people with RA in local communities to access support and education.
2. We will recruit and train additional volunteers in each year from 2014-2017 who wish to provide peer to peer telephone support.
3. We will increase our membership each year from 2014-2017, and our HealthUnlocked Community to enable many more people to take advantage of the benefits that membership of both bring.
4. We will launch a new website in spring 2014 to enable visitors to find information more easily and to interact more individually. We will create new areas on the site to enable greater self management and self empowerment which will launch between 2014-2017.
5. We will increase our successful NRAS Roadshows over the next 3 years encouraging members to get more involved in our work.

By 2017

Our aim is for many more thousands of people to be aware of NRAS and able to benefit from our services and we will have developed additional tools and programmes which can be accessed via our new website including an area about cardiovascular risk and a foot health education programme.
Strategic Aim 4

We will pioneer information, education, training and support of health professionals in rheumatology

NRAS is the partner of choice for healthcare professionals caring for those with RA. Not only do we act as a professional information source of surveys, reports and statistics on patient needs and preferences, we also work collaboratively both nationally and internationally to share examples of both best practice and our own experiences of representing patients.

1. We will work hard to ensure greater take up of the free NRAS membership available to all healthcare professionals.

2. We will pioneer NRAS induction days for health professionals who wish to send rheumatology health professionals to spend a day with our team to find out more about how we can support their patients.

3. We will increase the number of NRAS groups enabling NRAS to provide support to a greater number of rheumatology units and teams.

4. We will offer a variety of education and training resources for healthcare professionals and work with all stakeholders, including the pharmaceutical industry, to improve patient communications and care pathways.

5. We will continue to pioneer other innovative ways in which we can raise awareness of the services NRAS can provide with organisations such as the Royal College of Nursing, The Chartered Society of Physiotherapy and British Health Professionals in Rheumatology.

By 2017

We will pilot and roll out a training programme for specialist nurses and allied health professionals on how to address and support the emotional and relationship issues which impact on those living with RA.
Strategic Aim 5

We will help to shape the national environment and policy direction

As the UK’s population continues to age and live longer, the effective management of long term or chronic conditions such as diabetes, cancer and mental health has become a key driver for successive UK Governments and for the NHS. At NRAS, our task is to ensure that the voice and concerns of people with RA continue to be heard by decision makers and policymakers nationally, in the face of many competing issues. We will continue to influence and help shape the political and policymaking environment to ensure that RA has equal status and priority with other long term conditions.

1. We will make campaigning to raise awareness of RA and the need for earlier diagnosis a priority amongst policymakers, commissioners of services, healthcare managers and key opinion leaders, with a greater emphasis on the devolved health economies than we have been able to do prior to the introduction of our Campaign Networks.

2. We will also campaign to promote and encourage the implementation of best practice, in line with national guidelines and standards, to improve the standards of treatment and care for people with RA, enhance patient outcomes and experience, and to reduce inequalities of access to best care.

3. We will continue to campaign both as NRAS and as part of a number of key coalitions within the field of welfare reform where we are very active.

4. We will produce at least one major new report each year from 2014-2017 on a subject of key importance to people living with RA, their families and carers, to support our above campaigns.

By 2017

We will have increased the number of quality incentives for RA in the NHS and improved the benefits system for people with fluctuating conditions. We will also have completed the roll-out of our Campaign Networks in Scotland, Wales and Northern Ireland to further our campaigning capabilities in the devolved nations.

Norman Lamb, Minister of State for Care and Support and Laura Guest, CEO of British Society for Rheumatology, present Ailsa Bosworth with the Rheumatology Best Practice Award for the NRAS RA Self Management Programme
Strategic Aim 6

We will work to sustain our organisation in every way possible to continue to evolve and grow

We have built a thriving and effective organisation which is fulfilling its aims. As part of that process, we recognise the importance of everyone who is part of the NRAS community – our staff, trustees, volunteers and Members. We want to develop and support all of these people as the charity grows, building a sustainable organisation which has the capabilities and skill sets to meet the needs of the growing community that we represent going forward.

1. Our aim is for our staff to be able to fulfil their potential so we will continue to invest in formal training and development opportunities for them, as well as providing informal opportunities for the team to learn from, and share with, one another.

2. We will strive to ensure that we provide regular opportunities for our members and volunteers to participate in mutually beneficial shared learning experiences, take part in a variety of events and also represent NRAS both in the UK and abroad.

3. We aim to do more to harness the enormous potential and enthusiasm of our volunteers and members, not only so that we can better serve the RA community, but to help them to fulfil their goals and aspirations.

4. To continue to grow and achieve our aims, we will invest in our fundraising capability, build new income streams and increase our reserves.

By 2017

By 2017 we will have appointed and trained several key new members of staff to improve our capabilities, competencies and efficiencies in the areas of fundraising, data management, youth liaison, information and communications, and directly commissioned services. We will also have grown our financial reserves sufficiently to meet up to 12 months’ operational costs.
Strategic Aim 7

We will launch a new service for children, families and young people with Juvenile Idiopathic Arthritis (JIA)

Until 2014, NRAS has provided only basic information about JIA on our website and yet it has always been our desire, since our launch in 2001, to provide a more comprehensive service for those affected by JIA. Funding obtained in 2012 enabled us to carry out a ground-breaking project to map the services provided for those with JIA across the UK. During 2013 we visited 32 units and interviewed health professionals, parents, young people and NHS Managers culminating in a major report which was published in February 2014. The information obtained through this process has helped us to shape what we hope will be a valuable service and resource for everyone receiving and providing care in regard to JIA. We cannot provide everything those we interviewed asked us for, particularly not from our launch date on 19th July, 2014. However, we will prioritise a limited number of key areas initially where we believe there are significant gaps and our service will evolve over time as funds and resources permit.

1. We will establish a JIA support team comprising a JIA Services Manager and a Youth Liaison Network Officer.
2. We will provide a comprehensive web area for families with children and young people affected by JIA, and for use by health professionals. This will identify evidence based pathways of care, describe what good care looks like and sign-post to organisations and other charities who can help. The website will launch later in 2014 and be an on-going work in progress as we build the various sections.
3. We will establish a Government Affairs aspects of the service to ensure that we are able to influence policy makers and those responsible for Specialised Commissioning in the new NHS landscape. We will also raise public awareness of JIA and the need for early diagnosis.
4. We will establish a Young People’s Network and a Parents’ Network to inform the development of our service.
5. We will work collaboratively with the paediatric rheumatology community and other charities in this field.
6. We will establish a fundraising programme to ensure the sustainability of the service.

By 2017

We aim to develop essential basic materials, new school based information and outreach services, have a very information rich web area, research and launch data and a Publication/Report concerning transition to adult care. By 2017, we hope to have become the ‘go-to’ organisation for everyone affected by and working in the field of JIA.
Strategic Aim 8

We will develop a range of services for people with RA which can be directly commissioned and to provide consultancy services to Clinical Commissioning (CCG) and Clinical Support Groups (CSG)

The move to the new commissioning landscape which is focused on patient outcomes rather than on targets, provides NRAS with opportunities to provide both consultancy and directly commissioned patient support services. As partners in The Musculoskeletal Support Alliance with the British Society for Rheumatology and Arthritis Care, we are already working successfully with two CCGs, providing consultancy services during 2014 and potentially beyond. As more CCGs seek to inform their commissioning intentions going forward, or issue tenders for rheumatology services, we have significant expertise to offer.

1. We aim to set up a new arm of the charity to deal with directly commissioned services and consultancy work, NRAS Community Services Limited. We hope that over time this will enable us to provide an additional income stream to directly support the work of NRAS for the benefit of all those living with and affected by RA.

2. We aim to further develop and strengthen the work of the Musculoskeletal Support Alliance (MSA) with our colleagues at the BSR and Arthritis Care.

3. We aim to increase the uptake of the RA Self Management Programme with our partners, self management UK, by training many more units to deliver this for the benefit of their patients.

4. We aim to develop further services and programmes which can be directly commissioned by the NHS for the benefit of people with RA.

By 2017

We aim to have successfully delivered and embedded innovative patient services and supported self management programmes in at least one region and developed outcome tools to be able to measure outcomes. We also aim to have increased the scope of our consultancy services with the MSA and develop a new income stream to support the work of NRAS.