

Impact Objectives

- Improve the lives of large numbers of adults and children suffering from any of the three paediatric conditions by measuring the patient's perspective of the effect of treatment
- Relieve the economic and health burden the condition causes young people and society by improving the understanding and impact of diagnosis and treatment
- Raise awareness and ensure a more widespread recognition of the conditions, enabling timely diagnosis and appropriate treatment through the design and implementation of an effective diagnostic tool and through improved education of clinicians

Hip conditions in the young – effective management strategies

A new collaborative network, led by Dr Tina Gambling, is filling in some vital gaps in our understanding of paediatric hip conditions (PHC). This research aims to improve young people's lives by enhancing knowledge and awareness of PHC



What are paediatric hip conditions, and who is affected?

PHC encompasses three conditions affecting young

people. Perthes disease is a condition affecting the hip joint in children. Part, or all, of the femoral head (top of the thigh bone and the ball part of the ball and socket hip joint) loses its blood supply and may become misshapen. This can lead to arthritis of the hip in later years. Perthes is rare (1 in 9,000 children are affected).

Another condition is 'Slipped Upper Femoral Epiphysis' (also called 'SUFE'), a condition involving the hip joint. With a SUFE, the growth plate (called the epiphyseal plate) at the top of the femur (thigh bone) is weak and the head of the femur or ball slips downwards and backwards. The exact cause of this condition is not known, but there may be a link between increased weight and hormonal changes during puberty. SUFE is relatively common and occurs between 0.2 and 10 per 100,000 population. It is more common in boys (60 per cent) than girls with the mean age at diagnosis being 13.5 years in boys and 12 years in girls.

The third condition is hip dysplasia (HD), which occurs when the hip socket is too

shallow to provide adequate coverage of the femoral head. It can also be poorly orientated. It causes a spectrum of hip joint defects ranging from mild instability through to frank dislocation. The abnormality leads to altered joint biomechanics. The structural damage which ensues leads to very premature osteoarthritis which can result in people as young as 18 years of age requiring a total hip replacement – a procedure with limited longevity. Hip dysplasia that needs treatment occurs in approximately two to three children per thousand. However, some studies have detected mild instability in up to one infant in six.

Did the involvement of paediatric patients in your research present any particular difficulties?

We adopted patient centred data collection methods, allowing these young people to present their own experiences directly. This was driven by the rich insights provided by the children (aged 6-18 years) who presented at our Economic and Social Research Council (ESRC) Seminar Series, along with our collection of young patients' stories. Three young patients told of their experiences and the impact of their PHC on their lives. This was followed by presentations from three sets of parents with their children. Key emerging factors

included: late diagnosis; being taken seriously by the GP and other clinicians; effects on the whole family and the stress incurred; lengthy time out of school/work; and psychological impact and damage.

How do you plan to make your findings accessible to the medical community and general public, particularly patients?

We will inform patient and clinical communities via websites, newsletters, meetings and conferences. Links to our ESRC Seminar website will be made from the International Hip Dysplasia Institute, the patient support charity 'Steps', DDH UK and the hip dysplasia Facebook page and other web based hip forums. The collaboration will be actively involved in promoting the use of the tools and outcome measures.

For the research community, peer reviewed publications will be submitted to journals including: Bone and Joint Bone Surgery (British), Hip International; and the Physiotherapy Journals. Findings will also be presented at appropriate conferences, publications and through national and international clinical networks: the British Hip Society and the Chartered Society of Physiotherapists.



Understanding and effectively managing paediatric hip problems

A new collaborative project, Paediatric Hip Conditions (Psychosocial and economic dimensions of impact on quality of life), is filling in vital knowledge gaps around the understanding, treatment and social consequences of these conditions affecting children

Paediatric hip conditions affect a significant proportion of the population between birth and adulthood, and can have a serious impact on the lives of young people affected. The social and psychological consequences can be severe, ranging from missed schooling and potential academic underachievement and restricted career options in adulthood, to feelings of isolation and self-consciousness at not being able to participate in the same physical activities as one's peers. Overall, being diagnosed with a hip condition as a young person – which might take place at birth, or later in childhood – often means an early life full of medical intervention, hospital stays and extensive periods of rehabilitation (6-12 months), and can be extremely difficult, not just for the young person but also their parents. Interrupted education or career progression and increased care needs often mean that the parent must take time off work or other activities to devote to their child's care. In the case of Perthes disease, for example, the condition and treatment can be so painful that there are serious psychological consequences. Dr Tina Gambling, the project's Principal Investigator, notes: 'We have identified that these children can also be in considerable pain which is distressing for both the child and their parents. Children can also suffer the lasting effects of undergoing

treatments, such as post-traumatic stress disorder, and they can become very distressed when they have hospital appointments'.

The treatment for these conditions is a matter of significant clinical debate. Surgery is the most common treatment, aimed at repositioning the hip and/or preserving the life of hip joint, for example, by periacetabular osteotomy (PAO), which is an operation to change the orientation of the hip socket so it is in a better position to cover the ball of the hip joint (femoral head) which improves joint stability. Without appropriate treatment, an early total hip replacement is likely.

Central to studies in this field is the question of joint longevity. Patients who have hip surgery in childhood require a solution that will be effective for many decades and at a high level of activity as is normal for young people. So the considerations are quite different from those involved where an elderly patient has their hip joint totally replaced.

The Paediatric Hip Conditions (PHCs) project takes a broad approach, looking at the psychological and social impact of clinical questions such as which surgery to choose. This interdisciplinary approach was possible because of the range of professionals

involved. The effective collaboration, led by Cardiff University, includes the University of Leeds, Birmingham Royal Orthopaedic Hospital and Alder Hey Children's Hospital. The collaboration was further enhanced by working in close association with the STEPS Charity, DDH UK, young people and their parents or carers.

CHILD CENTRED RESEARCH

Whilst PHCs are common, they have thus far received only limited research attention from a holistic point of view. As Gambling points out, 'unlike other paediatric conditions with similarly long lasting impact such as scoliosis, epilepsy and cystic fibrosis, there has not previously been a good understanding of how young people with paediatric hip conditions live with and manage symptoms, prepare for surgery, cope with post-surgical recovery or how they adapt to life with a PHC.' One of the primary aims of the team was, therefore, to understand from the point of view of young people and their families what life with a PHC looks like. To this end, one method of data collection was a self completing, readily comprehensible booklet for PHC young people to complete. The team also heard the



We aim to highlight the importance of understanding the trajectory of these conditions

opinions and experiences of young people with a PHC.

A main aim of the research is to develop an outcome measure, known as a PROM (patient centred outcome measure), which captures the quality of life impact of paediatric hip conditions in adult populations. The data collection for this project is taking place in Royal Orthopaedic Hospital Birmingham (ROHB). The data collection for the validation of this tool is now nearing completion. As Gambling explains, 'this tool will provide information on the severity of the disability and the benefits of prompt diagnosis and treatment from the patient's perspective. This will inform us of the efficacy of treatment because the tool is sensitive to young, active people's needs'. Once a PROM is in place, it gives a vital framework within which the impacts of various treatments and other interventions can be assessed.

Part of the project was a seminar series, which brought a number of useful perspectives to the issue. The team noted in particular the importance of a wide, international view. This is particularly important given the diversity of screening procedures and treatments, and the question of different care systems in place in different countries.

EARLY INTERVENTION IS KEY

One key finding of the study was the importance of timely treatment. 'We highlight the physical, social and economic burden of and for those affected by these conditions, and in particular to recognise and understand the trajectory of these conditions and to accelerate recognition enabling early, more effective treatment', explains Gambling. In this way, the wide-ranging focus of the research, which encompasses clinical insights as well as the broader questions of wellbeing and social issues, is underlined.

In the case of dysplasia, the most common condition of the PHCs in the study, the team heard of difficulties in receiving a diagnosis. This delay in treatment had wide-ranging negative effects on young people. Over the course of the seminars, notes Gambling, 'it became very apparent dysplasia is an under-recognised condition'. Young people described how their school, work and family lives were affected, and even their fertility – many young people in this category are young women of child-bearing age.

Some of the difficulties faced by PHC young people were systemic, and related to differing access to specialist hip centres in order to facilitate a timely diagnosis. The international perspective gained meant that the team was able to identify some 'best practice' locations, such as Coventry and Austria.

EFFECTIVE MEASUREMENTS, SCREENING TOOLS

The data collection and seminar series are leading to the development of an effective measure with which to assess the impact of PHC over the trajectory of the whole illness. This will be of direct benefit to the young people, as it can be used whilst considering different treatment options. As Gambling also notes, the research shows 'a need for a major preventative strategy which involves national neo-natal hip ultrasound screening, including robust training of the clinicians carrying out the screening'. Part of the team's research also centres on the development of a checklist for the early diagnosis of hip problems, so that non-specialists can be quickly alerted to any potential signs of PHCs. This is particularly important as misdiagnosis can lead to treatment which is counter-productive.

Project Insights

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PROJECT PARTNERS

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PRINCIPAL INVESTIGATOR BIO

Dr Tina Gambling is Director of Post-Graduate Studies at the University of Cardiff, and has published in the area of patient experiences of hip dysplasia and their responses to diagnosis. Her particular field of interest is psychological behaviour change, self-management in chronic disease, outcome measurement and theoretical constructs of patient centred care. Her background is in Psychology. She has developed a young person's outcome measure for those suffering a PHC and her work has now moved into the area of validating child friendly outcome measures, in collaboration with Professor Andrew Long at the University of Leeds.



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