

**Individual Funding Request Policy**  
**[Department of Health]**  
**Draft Consultation Response from Fermanagh and Omagh District Council**

## **Brief Background to the Fermanagh and Omagh District Council Area**

The District Council area is home to 114,992 people, approximately 52,500 jobs and 7,175 businesses. The District Council area is Northern Ireland's largest region in terms of land mass - approximately 3,000km<sup>2</sup> (or 20% of NI) - and is the smallest in terms of population. As a result, the population density of approximately 41 people per km<sup>2</sup> is the sparsest in Northern Ireland. This is a key feature of the district but presents challenges in terms of accessibility and service delivery.

## **Consultation Response**

Fermanagh and Omagh District Council (Council) welcomes the opportunity to respond to the Department of Health's public consultation on the 'Individual Funding Request (IFR) Policy'.

The Council believes that this Policy will play a vital role in the effective development of Health and Social Care (HSC) services in Northern Ireland. Not only will it have a significant impact on individuals accessing the HSC services, but it will also impact upon consultants and HSC services.

The Health Care industry is ever-evolving and new treatments are being discovered and made available frequently. Therefore, it is essential that guidance, policy and procedures are applied consistently, and clearly detail the processes for decision-making in relation to purchasing these types of treatments.

The Council agrees with the introduction of an IFR Policy; however there are some key differences to IFR Policies from other areas of the United Kingdom which should also be considered.

## **Applications for IFR**

The process, as outlined within the consultation documents, states that IFR requests should be made by a patient's hospital consultant, if they believe that a treatment or service (that is licensed but is not routinely offered by the health service) is the best treatment given the clinical circumstances.

The Council notes that this process is different to that in other parts of the UK, where applications can also be made from an individual's G.P. and recommends that this approach should be reconsidered.

If the final IFR Policy does not include a mechanism for G.Ps to make IFR applications, there should be provisions made for feedback to be sent to a patient's G.P. Often a patient will spend a substantial amount of time with their local G.P and may feel more comfortable discussing their options, or treatment, with them.

The IFR Policy should therefore be very 'patient-centred' and revolve around the best needs of each patient on a case by case basis.

Within the draft policy document, it states that all correspondence will be 'copied to the referring Consultant, Medical Director and Service Manager'. It also states that 'normally a patient should be offered a copy of the referral form'. The Council believes that a patient should **always** receive a copy of the referral form, as well as it being explained in detail. It is vital that each patient understands their individual referral/request, as well as the proposed treatment and medication.

### **Timeframes and Transparency**

Although, it is essential that procedures are put in place in order to ensure that the IFR process is appropriately administered, it is vital that this does not add extra waiting time, unnecessarily, to a patient waiting on treatment, a service or medication.

Whilst the Department speaks of a 'timely decision' being made and 'providing treatment under the IFR process within a reasonable timeframe', the Council believes that the Department should put a maximum timescale on this process – not only would this aid those consultants who are initiating the request, but it would also give the patient an idea of when they will discover if the request for a treatment or service has been successful.

The process should therefore include standard response times, rather than targeted timescales – reassuring patients that they will not have to endure lengthy waits in relation to decisions regarding their treatment.

The Council acknowledges that the 'Individual Funding Request' process will necessarily entail making difficult decisions. It is therefore, vital that the public (and patients) have full confidence in the process; increasing transparency in the process should help to promote this.

In previous years, there have been reports and evaluations which have outlined several concerns with existing processes including:

- Perceived inequity of access to treatment and medicines (such as cancer medicines) in comparison to models in other countries i.e. England and Scotland.
- A risk of variable decision-making due to differing approaches.
- The process lacking transparency and not placing sufficient emphasis on clinical input.

The Council strongly recommends that the Department works with various organisations in partnership to ensure that there is absolute clarity and transparency within the 'IFR' process. These organisations would include the Health and Social Care Board, the Health and Social Care Trust, the Patient Client Council, G.P representative organisations as well as the public.

## **Cohorts of Patients**

The Council is mindful of the fact that this policy refers to Individual Funding Requests and not for requests which may lead to applications from a cohort of individuals who may be in similar circumstances, or whose clinical condition means that a similar request could also be made.

In instances where the 'Individual Funding Request' has identified a potential cohort of patients, the consultation document states that the 'Regional Scrutiny Committee (RSC) will refer to the relevant commissioner' for a timely decision.

At present, until the Commissioning Position is being considered, the RSC will continue to provide that treatment under the IFR process. The Council recommends that the IFR Procedures, as well as the various Commissioning Positions, must be developed in tandem with each other. This may prevent having to amend the procedures further down the line, as well as offering further clarity to everyone involved within the process – including consultants, patients and decision-makers.

## **Regional Scrutiny Committee and Transparency**

The Council believes that the system, and procedures, should be both transparent and accountable. This will help to promote confidence in the procedures, as well as the decisions which are made.

There are many various examples, from across the UK, in relation to IFR and similar processes – for example, in Scotland a 'Peer Approved Clinical System' was introduced. The Department should adopt the various examples of good practice from across the UK, especially those which promote effective decision-making.

Transparency in all decision-making will be essential to ensure patient expectations are met – the Council believes that all patients have the right to understand the basis on which decisions are made to either treat or withhold treatment.

The Department should ensure that the 'IFR' process is introduced as a Northern Ireland wide process, placing emphasis on clinical need and peer review – although ensuring that this does not constitute another level of bureaucracy which may inject further delays. Therefore, there should be a guarantee that all 'Regional Scrutiny Committees' are conducted in accordance with uniform procedures and governance, and consider the same criteria, regardless of where they are being conducted or from where the 'IFR' originates.

Individuals not only need to know that decisions on their treatment are being made on clinical need, but that they should also be ensured that their access to medicines/treatment that may benefit them is not limited by where they live – particularly in the more rural parts of Northern Ireland.

## **Fermanagh and Omagh 2030 – Community Plan and Future Proofing**

The Fermanagh and Omagh 2030 Community Planning document, references 'Health' in several places.

The Council's Community Planning process developed a number of key 'outcomes' against each of the evidence based priorities. The first 'priority' identified within the Fermanagh and Omagh 2030 document is 'Physical and Mental Wellbeing', with the associated 'outcome' being described as 'Our people are healthy and well - physically, mentally and emotionally'.

Statistics demonstrate that the population of the Fermanagh and Omagh District is aging. Currently, 15% of the local population is aged 65 years or above, and this is expected to increase to 23% by the year 2030. This will create additional pressures upon public services including those within the Health Care sector such as the IFR process.

The Department should ensure that sufficient funding is allocated to the 'IFR' process within each financial year, and that this funding is ring-fenced. There is a need for a well-defined sustainable funding mechanism for new medicines/treatments as well as ensuring there is appropriate infrastructure to deliver this (i.e. medical, nursing and pharmacy staff) within each area – particularly within the Fermanagh and Omagh District Council area.

The Fermanagh and Omagh 2030 Community Plan states that the overall vision for the District is to ensure a '...welcoming, shared and inclusive Fermanagh and Omagh district, where people and places are healthy, safe, connected and prosperous...'. The IFR process will play a role in ensuring the health and wellbeing of individuals, with examples including access to new cancer drugs, new treatments and new specialist mental health services, amongst others

### **Conclusion**

The Council welcomes the opportunity to respond to the Department's consultation on the 'Individual Funding Request Policy'.

The Council acknowledges the importance of this policy in ensuring that patients have access to appropriate treatments, medicines and/or services and believes that for the procedures to be successful there needs to be consistency, transparency and accountability, with an emphasis placed on clinical review.

The Department, along with other organisations, is a key partner within the Council's Community Planning process, and the Council looks forward to continuing this partnership to delivering the best future outcomes for the District and its local community.