Medicines & Healthcare products Regulatory Agency

Engagement with Patients

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Patient Group Consultative Forum (PGCF)

Established in the Autumn of 2014.

Underpinned by the recognition that:

Patients bring expertise, specialist knowledge/insight – this will assist the agency in the development of regulatory processes and decision-making.

PGCF - Purpose

Provide an established forum through which the agency can engage in meaningful dialogue with patients, their carers, patient groups and members of the public.

Thereby:

- Support the MHRA Corporate Plan to achieve its aims relating to ‘partnerships’, ‘innovation’ and ‘vigilance’.

- Support the wider strategic objectives of safeguarding patient safety and improving public health.

PGCF - Composition

Members recruited initially through approaches made to charities and other not-for-profit organisations representing patients or particular health constituencies.

Subsequent members added through patient networks and other patient groups encountered through the work of the PPSE team.

Currently 80+ individual members representing around 30 different primary health issues and long term conditions.

PGCF - Rules

- Open to people with an interest in medicines and medical devices and patient groups who can find out the views of their members and feed these views into the PGCF.

- Role description – clear contract:
  - Ability to draw on experiences as a patient and as a consumer of medicines and medical devices and translate this into a population level perspective.
  - An interest in championing patient safety.

- Avoidance of bureaucracy – PGCF kept as informal an arrangement as possible.

Input to date

- Improving patient/public reporting of adverse incidents with medical devices.
- Patient/public understanding of the reclassification of medicines.
- Accelerated Access Review – patient attitudes to risk/benefit of medicines.
- Patient views on the packaging of medicines.

- Upcoming:
- Patient views on medical device design/instructions for use.
- Regenerative medicine - patient attitudes to pathways to innovation in medicine.

UK Reclassification Stakeholder Platform

- To advise on strategies and processes that will ensure maximum engagement of all stakeholders in the reclassification of medicines.

- Composed of:
  - Pharmacists and GPs.
  - CPOs/Devolved Administrations.
  - Lay representatives/patients.
  - Industry (as observers).

Other engagement with patient groups

To support MHRA's position/action taken and help spread the message to groups otherwise hard to reach:

- Medical Device Alerts, e.g. insulin pump.
- Medicines warnings, e.g. sodium valproate.

Agency Board – public sessions.

Multi-stakeholder events:

- Human Factors 'open day' – guidance.
- Genomics 'open day' - strategy development.

PGCF development - tactical

- Growth – number of members, especially actual patients.
- Expansion – range of health constituencies.
- Recruitment methods –
  - increased public profile.
  - word-of-mouth.
  - targeted approaches.

PGCF development - strategic

- Raise internal profile – embed the PGCF in agency processes and projects.
- Raise external profile (e.g. Cross-UK Partnership Forum).
- Support the agency in meeting government expectations for greater patient/public involvement (Accelerated Access Review, Personalized Medicine Strategy).
- UK-wide role?
- International networking?